DYING WITH DIGNITY: DIFFICULT TIMES, DIFFICULT CHOICES

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HOUSE OF REPRESENTATIVES

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DYING WITH DIGNITY: DIFFICULT TIMES, DIFFICULT CHOICES

TUESDAY, OCTOBER 1, 1985

House of Representatives,
Select Committee on Aging,
Washington, DC.

The committee met, pursuant to notice, at 10 a.m., in room 345, Cannon House Office Building, Hon. Edward R. Roybal (chairman of the committee) presiding.

Members present: Representatives Roybal, Biaggi, Ford of Tennessee, Hughes, Lloyd, Mica, Vento, Frank, Gordon, Snowe, Wortley, McCain, Boehlert, Bentley, Meyers, Blaz, Henry, Kolbe, and Schuette.

Staff present: Fernando Torres-Gil; staff director, Gary Christopherson, professional staff; Christinia Mendoza, professional staff; Joan Densberger, professional staff; Nancy Smith, professional staff; Judith Lee, executive assistant; and Carolyn Griffith, staff assistant.

OPENING STATEMENT OF CHAIRMAN EDWARD R. ROYBAL

The **Chairman**. Ladies and gentlemen, today's hearing is being held on behalf of those who have a terminal illness and cannot be here with us to share their concerns. They cannot share with us the conflicting pressures that they face and the difficult choices placed upon them as well as their families, their friends, their physicians, and society as a whole.

This issue is critical. We consider that the terminally ill have been placed in a "Catch-22" situation. On the one side are the pressures from policymakers who cite the high cost of caring and from some who imply that the terminally ill have a duty to die. On the other side are the health care providers who press the terminally ill to not refuse medical treatment and to live as long as modern medical technology will allow. The terminally ill are trapped in the middle. They are, indeed, trapped in a "Catch-22" situation. The purpose of this hearing is to make the public and the Congress aware of these conflicting pressures and to find ways to relieve these conflicting pressures for the elderly and nonelderly persons who are dying.

Clearly, these pressures on the terminally ill need to be reduced. State and Federal governments need to act to reduce cost-related pressures on those who have terminal illness and to give them the legal vehicle which will give them adequate control over their final days. Further, now is the time for physicians and other health care providers to become even more sensitive to and supportive of the final wishes of America's terminally ill.

In this hearing and in a special study released today, we have described the dilemma facing America's terminally ill persons. This is one issue that is frightening not only for those who are ill, but those of us who are not ill. No one is exempt from dying and nothing is more important than to preserve the dignity of life. Many of us in this room are still able to assist those who have a terminal illness and to better prepare for our own deaths. Let's act positively and let's act quickly.

This is a most important subject as expressed in today's hearing title: "Dying With Dignity: Difficult Times and Difficult Choices."

And we have today four distinguished witnesses who will present their views in just a few moments. But before we do that, the Chair would recognize Congressman Henry.

STATEMENT OF REPRESENTATIVE PAUL B. HENRY

Mr. **Henry**. Thank you, Mr. Chairman. I commend you on really a very succinct statement of the dilemma that faces us. Clearly, the frontiers of modern science and medical technology have imposed on us ethical choices for which few of us are prepared. Few of us in the Congress and our society at large, medical health care providers, as we struggle to honor life, the dignity of life and, yet at the same time, there are new ways contending with the issue as to what is life; what is dignity and life. And we are contesting with our moral traditions in a way in which we have not had to do so before.

So I look forward to this hearing. I am sure it will be profitable. And I will ask Mr. Chairman, if I might, that other members of the committee and interested organizations would have an opportunity to submit written testimony for the record up to 2 weeks after this hearing.

The **Chairman**. Without objection, that will be the order. Anyone that wishes to submit testimony, that is not actually testifying, can do so in writing. It will be included in the report that will be made by this committee.

Ladies and gentlemen, our first witness——

Mr. **Hughes**. Mr. Chairman.

The **Chairman**. Mr. Hughes.

STATEMENT OF REPRESENTATIVE WILLIAM J. HUGHES

Mr. **Hughes**. Thank you, Mr. Chairman. I am pleased that the Aging Committee has chosen to examine this difficult and important issue. And I want to congratulate you on convening this particular hearing.

Progress is often a two-edged sword. Rarely are great advances made in any field that do not create problems in learning how to cope with them. This has never been more true than with the miraculous advances we have witnessed in medical technology over the course of our lifetimes.

There was a time, not so long ago, when there was nothing so clear as the distinction between life and death. We are grateful that modern medicine has enabled us to save and improve lives that could not be saved in the past, but it has also, to a certain extent, blurred the distinction between life and death, creating problems that could not even have been imagined 20 or 30 years ago.

We are faced with a number of extremely difficult questions. How do we strike a balance between the responsibilities of the medical community and, indeed, our society as a whole and the rights of the terminally ill? Who makes the final decision? To what extent should the Government involve itself in these particular issues?

We are fortunate to have the help of a number of excellent witnesses in examining these questions. I look forward to hearing their testimony, and I am particularly happy to see our illustrious Senator from New York. It is nice to see you, Senator.

I give back the balance of the time now.

The CHAIRMAN. Thank you, Mr. Hughes.

Mr. Gordon.

STATEMENT OF REPRESENTATIVE BART GORDON

Mr. GORDON. Mr. Chairman, I am very grateful for the opportunity to be present for this very significant hearing. The Select Committee on Aging has taken important steps to address ways to enhance the quality of life for older Americans. Yet no issue is more difficult than the one we face today. We need to hear from the terminally ill, their families, and health providers who care for them so that we in Congress may be more sensitive to their needs and wishes. We must ensure that their final days are filled with honor and self respect.

Hopefully, today we can begin to find some answers to the troubling dilemmas facing America's terminally ill.

The CHAIRMAN. Thank you, Mr. Gordon.

Mr. Wortley.

STATEMENT OF REPRESENTATIVE GEORGE C. WORTLEY

Mr. WORTLEY. Thank you, Mr. Chairman. I appreciate your calling this hearing today.

The subject of this hearing is undoubtedly one of the most difficult and emotional problems facing society today. It is difficult for the person who is dying, his or her family, and the doctors and other members of the health care team. Death and dying has been close to being a taboo subject in the past. I suspect because it is a subject which is unpleasant and disturbing, we have preferred to ignore it. This reluctance to face reality has augmented the problems and the trauma of an already traumatic situation.

I am encouraged by the efforts of this hearing to approach the subject of dying in a more open, compassionate and humane manner.

I would like to add my personal welcome to today's witnesses who are testifying here today to promote our common goal of allowing those who are dying to do so with dignity and with comfort. I would like to particularly pay a special tribute to my fellow New Yorker, the distinguished Senator Jacob K. Javits. Senator, it is an honor and a privilege to have you testifying before this committee today. In your own struggle, I wish you strength and God's blessing.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you.

The Chair will now request that anyone that has a statement to make, any member, that their statement be included in the record at this point. This is due to the fact that we must hurry on and hear from the witnesses that are the important people in this hearing.

[The prepared statements of Representatives Hammerschmidt and Snowe follow:]

PREPARED STATEMENT OF REPRESENTATIVE JOHN PAUL HAMMERSCHMIDT

Mr. Chairman, thank you for holding this hearing today so that we can look at the right-to-die issue and its effect on older persons, their families, and their physicians.

As members of the Select Committee on Aging, it's important for us to be aware of all issues concerning older persons, including those legislated on the State level. For this reason, today's hearing is timely. By examining the emotional and economic factors leading to decisions about whether a person chooses not to prolong his life through life-sustaining apparatus or medical treatments, I'm hopeful that we can better understand the growing trend toward these decisions by older persons. In addition, we can better understand the role of State courts and legislatures in this decision making process.

Because of advances in medical technology, ways have been developed for keeping people with terminal illnesses alive for long periods of time. As a result, many ethical and economic decisions not previously at issue have arisen. It's important to note, however, that currently the laws pertaining to death and dying are State laws. It's my understanding that the State have been looking at these issues for some time now and have responded legislatively when necessary. It would seem then that this issue is one which may best be left under the jurisdiction of State legislatures. They, more than the Federal Government, are aware of the attitudes of their respective States, and thus may be better able to make laws pertaining to sensitive issues such as death and dying.

Mr. Chairman, thank you again for holding this hearing. I'm looking forward to hearing the testimony for our distinguished witnesses.

PREPARED STATEMENT OF REPRESENTATIVE OLYMPIA J. SNOWE

Thank you Mr. Chairman. I want to commend you for holding this hearing on a very important topic which we as a society tend to shy away from—how to cope with the inevitability of death.

I also want to say how pleased I am to again see my friend, the Honorable Jacob Javits. We all know of the outstanding contributions he made in the Senate and the energy and dedication with which he served. I think we should also praise his continued work in the field of foreign affairs and on other issues of concern.

I know the members look forward to his participation today as we discuss this very important topic—dying with dignity.

The notion of the right-to-die is peculiar to our times. While the issue is not new, modern technology has changed our understanding of life and death. To the fear of dying we have now added the fear of dying without dignity. We have grown to view with horror the dying process more than death itself. Being left as a helpless patient in an institution, subjected to invasive treatment, even though there is no hope of recovery, is a powerful image. This fear has lead to the formation across the Nation of "right-to-die" organizations with the goal of obtaining legislation to provide the terminally ill person, who no longer is able to communicate, with some control over dying process.

Until recently, to die was not generally conceived of as a right. To die was everyone's fate. To die "well" was to die with courage, faith and resignation. Today, to die "well" has taken on a different meaning. In the case of the terminal patient without awareness or prospect of regaining it, dying "well" means being allowed to die without being sustained by artificial means.

The Living Will is a declaration which allows a person to instruct his or her physician to withhold extraordinary medical treatment in the final stages of a terminal illness. These wills have been adopted in 35 States and the District of Columbia and are being considered by all but two of the remaining States. An example of a Living Will is the one adopted by my own State of Maine just last month. It reads:

"If I should have an incurable or irreversible condition that will cause my death within a short time, and if I am unable to participate in decisions regarding my medical treatment, I direct my attending physician to withhold or withdraw procedures that merely prolong the dying process and are not necessary to my comfort or freedom from pain."

I think it is important to emphasize that we are not talking about leaving the patient in pain or discomfort, but rather providing only the necessary medication or equipment to make the patient comfortable during his or her final moments.

While the Living Will provides us with an important ingredient to assist us in decision making, problems may still arise. In many situations, the Living Will legislation has not been sufficient to guarantee patient's rights. The next step is, therefore, to designate a family member, friend or other individual to speak for the patient if he or she is no longer able to communicate. Although all 50 States have provisions for designating a durable power of attorney, only about 10 States have extended the power into the medical context. From the patient's perspective, an agent would help to assure that an incapacitated patient receives treatment in accordance with his or her own wishes.

As it becomes more and more complex to define the biological boundaries of human life with the advance of technology, it also becomes increasingly important for the individual to have the right to determine at what point he or she wants to die and thereby maintain dignity in death.

Mr. **Roybal**. The first witness is a former Senator from the State of New York. He served in the Senate of the United States from 1957 to 1981. And may I say that he established an excellent record as a U.S. Senator, a fighter for the rights of the people.

He at present is an attorney, or has been an attorney for a long time, and has offices here in Washington, DC, and also in New York. But he is here to make a very important presentation.

Senator Javits, may I welcome you to this committee. Thank you, first of all, for all you have done. I know of your work since you left the Senate of the United States. I would like to welcome you and ask you to proceed in any manner that you may desire.

STATEMENT OF HON. JACOB K. JAVITS, FORMER U.S. SENATOR FROM THE STATE OF NEW YORK; ACCOMPANIED BY BARBARA MISHKIN, ATTORNEY

Senator **Javits**. Thank you, Mr. Chairman.

I am accompanied today by Ms. Barbara Mishkin, who is a lawyer in Washington with the firm of Hogan & Hartson, and who was Deputy Director of the President's Commission on Ethics in the Medical Profession; and addressed herself in many cases to the subject we are considering in this hearing. I consider Ms. Mishkin an authority on the case law which is involved. And she will be advising me on that subject as we go along.

I would like to thank the members who have appeared this morning and thank the chairman for conducting and inaugurating this hearing on the House side, and thank those members who have addressed themselves to this subject.

I served here for four terms in the House, and I realize the range of responsibility. And I am grateful that so many members have shown up this morning. I thank especially those from my neighboring States, New York and New Jersey, for their interest and the nice things they have said about me. I also thank the chairman.

My statement is as follows.

The United States is now coming into a greater maturity about dying. It must be understood that as an adult people, all of us are terminal, and that as the Bible teaches, the road which opens with birth leads to the grave. Birth and death are the most singular events we experience and, therefore, the contemplation of death as of birth should be a thing of beauty.and not of ignobility.

The new factor that has come into our lives is medical technology which can sustain life even when the ability to decide for oneself or the competence to do so, when the brain is gone, are not present. It is for this reason that public policy and rational morality and humanity demand that we organize our society so that the right to die may be accompanied by that dignity which equals the joy of birth. It is for this reason that laws are now established in many States to implement this concept.

I am personally in the position which concentrates the mind on this subject because I am afflicted with a terminal illness. And so I take a profound interest in this subject, and believe, Mr. Chairman, that legislation at the Federal and State level is very much in order in dealing with the dilemma which you have referred to in your opening statement. And one of the ways in which this can be done is through ascertaining the wishes of the individual who is facing this awesome decision.

In this area, I believe that living wills and durable powers-of-attorney can be very helpful. They are—living wills, or what are called a desire for a natural death, are now recognized under the laws of 35 states and the District of Columbia. My written statement specifies the States which do not as yet have living will laws. They include my own State of New York, which is now considering such a statute.

Under the living will laws, an individual may, when mentally competent, make a decision as to medical treatment, and certainly when competent enough to have made an ordinary will, leaving property, et cetera. Under these laws and under such a living will, which, as I say, has no more formality than the ordinary testimentary disposition, one can determine for himself that when he has lost all mental power to decide on whether life-sustaining equipment should be used to extend his life, whether that equipment may be withdrawn with his consent even though at the time of withdrawal he or she is no longer competent mentally to express a will as to the disposition of his own body.

A living will may, of course, be revoked or may be challenged in the courts if abused. For example, if it is contended and proven by clear and convincing evidence by a relative or a spiritual adviser or by the State, that under the circumstances if then competent to decide the individual would have decided otherwise or if for reasons of public policy—for example, the continuance of an obligation to support minor children—the individual would not have decided as he did by his living will, then the courts could order it revoked. Nothing, of course, can be more important than the right to life and the right not to have it terminated prematurely.

But the important aspect of a living will is that when a person knows what he wants done with his own body, he can make that decision binding if he then loses the mental competence to decide when the issue is presented.

An alternative to the living will now lawful in every state except, interestingly enough, the District of Columbia is a durable power of attorney. Under it, an individual, friend, relative, physician, legal, or religious adviser or a court may be granted authority to make medical decisions when the person concerned is no longer competent to make them. And here, too, abuse may be prevented by recourse to the courts.

Now, I have read the memorandum to which the chairman referred of the catch-22 situations in which individuals facing the end of their lives are caught. And they are heavily premised on the economic equation. Indeed, not so long ago, Governor Lamm of Colorado suggested that people with no real prospect of living ought to get out of the way and stop using precious medical resources to be kept alive. It sounded callous and probably was, but the Governor was uttering a truth. Even in this great Nation where living or dying should have nothing to do with money, it still is a fact that it does, and very materially. And that is what makes the right to die with dignity an issue of morality and humanity as well as of policy and law. The cost of medical care with its new technologies is now so great that only the use of the insurance principle on a national or sectional basis can allow the optimum result of equal care for all to prevail in our country.

And so this committee should not only consider a legal disposition like the living will or the durable power of attorney, but also how to deal with the inequities of the cost which brings about inequalities in medical treatment.

I suggest two possibilities. One is to allow the individual to convert a good deal of what is available to him or her under a Governmental program, like Medicare and Medicaid, into home care; this being the great area where help is possible and which is now inhibited under the law. And the second is the hospice program, which should also be recognized as a feasible alternative.

I close by calling attention to the confusion and confrontation which takes place in families if the individual who faces death and is no longer able to make his own decisions has not left the necessary instructions in a living will or a durable power of attorney. I point to the heavy responsibility borne by doctors and the medical profession and by hospitals and other medical institutions in this highly litigious society of which we are a part, in the absence of some effective indication of whether the individual himself wants to live, even if he is a vegetable or whether he has made the decision to have it over with if all hope is gone.

So these legal instruments are one way to help. And the other is to have a more sensible and realistic system of giving what the Government is already willing to give, to give it more intelligently.

Mr. Chairman, this is a vital question of dignity and morality. And I hope very much that the committee will be dealing with it accordingly.

Thank you, Mr. Chairman.

[The prepared statement of Senator Javits follows:]

Prepared Statement of Hon. Jacob K. Javits, a Former U.S. Senator From the State of New York

The United States is now coming into a greater maturity about dying. It must be understood that as an adult people we are all terminal and that as the Bible teaches, the road which opens with birth leads to the grave. Birth and death are the most singular events we experience and therefore the contemplation of death as of birth should be a thing of beauty.

The new factor that has come into our lives is medical technology which can sustain life even when the ability to decide for oneself or the competence to do so—when the brain is gone—are not present. It is for this reason that public policy and rational morality and humanity demand that we organize our society so that the right to die may be accompanied by that dignity which equals the joy of birth. It is for this reason that laws are now established in many states to implement this concept.

Living wills are now recognized under the laws of 35 states and the District of Columbia. Only the states of Alaska, Hawaii, Kentucky, Massachusetts, Michigan, Minnesota, Nebraska, New Jersey, New York, North Dakota, Pennsylvania, Rhode Island, South Carolina and South Dakota do not as yet have such laws. Under such laws an individual may when mentally competent to make a decision as to medical treatment or certainly under the same tests as are applicable to the validity of a traditional will leaving property, appointing guardians for children, and establishing trusts for charity, education and research, determine for himself if when he has lost all mental power to decide on whether life sustaining equipment shall extend his life even though there is no probability of recovery he wishes that the equipment be withdrawn and allow nature to take its course.

Such a living will may of course be revoked or may even be challenged in the courts if abused. For example, if it is contended and proven clearly by any party in interest, including the state, that under the circumstances if then competent to decide the individual would have decided otherwise of if for reasons of public policy the individual living will should be considered to be revoked. Nothing could of course be more important than the right to life and the right not to have it terminated prematurely.

An alternative method now lawful in every state, though not yet in the District of Columbia, other than a living will, which may well be a method preferred by many, is the durable power of attorney. Under it an individual, friend, relative, physician or legal or religious adviser or a court may be granted authority by an individual to make medical decisions when the person concerned is no longer competent to make them. Here too, abuse may be prevented by recourse to the courts.

Finally there is the question of money and medical resources and how they should be allocated. Many people were shocked when Governor Lamm of Colorado urged individuals who had no real prospect of living to "get out of the way" and stop using medical resources to be kept alive, which might more profitably be used by others. This sounded callous and probably was but the Governor was uttering a truth. We have not yet reached the point even in this great nation of ours where living or dying has nothing to do with money. That is what makes the right to die with dignity an issue of morality and humanity as well as of policy and law. The cost of medical care with its new technologies is now so great that only the use of the insurance principle on a national or sectional basis can allow the optimum result of equalitarian medical care for all on a reasonably equal basis. We are also quite behind the need in providing home care for the ill and disabled in a setting which maximizes dignity, rather than institutionalization. The hospice program is also one to be seriously considered in this connection.

One other factor deserves high consideration in this matter of living wills and durable powers of attorney. This factor is decision making by families who generally carry the responsibility in the absence of competence of the individual afflicted. Such decision making can be the cause for much confusion and even confrontation. In fact the laws of only twelve states give families the responsibility for such decisions. In others while family decisions may be recognized as important they are not binding. This leaves a heavy responsibility on the medical profession, hospitals and other medical institutions in such decision making especially in our litigious society and creates conditions of uncertainty, inconsistency and injustice. These problems cannot be eliminated, but they can be greatly assisted by the more widespread use of living wills and durable powers of attorney.

[From the New York Times, Aug. 18, 1985]

LIFE, DEATH AND HUMAN DIGNITY

(By Jabob K. Javits)

I may be terminally ill. I therefore face, in an intimate and personal way, the issue of my right to die. I am happy for those who are not ill, but they are terminal too and they should think about this question as it relates to themselves and those they love as friends or simply fellow human beings.

The issue first received serious attention 10 years ago, when a New Jersey court granted Karen Ann Quinlan's parents' request to remove life-preserving support from their comatose daughter. There has, since then, been an intensive inquiry into the ethical and legal aspects of the right to die.

The issue is whether a terminally ill patient may confer the authority to withdraw his life support. This is generally done by means of a living will, written when the patient is still competent, that transfers authority to a designated relative, friend, physician, religious or legal adviser or to a court. Thirty-five states have now passed living-will laws, 22 of them in the last decade.

The question arises in the case of any serious illness—including cancer, heart attack and a whole range of neurological and neuromuscular diseases—that deprives the patient of the ability to decide what is to be done for him. But once illness has stuck, it is often too late: the pateint is often no longer competent to express a will.

Birth and death are the most singular events we experience—and the contemplation of death, as of birth, should be a thing of beauty, not ignobility. Everyone must think about dying, young and old alike, though older people are at greater risk. Given the new medical technology that can sustain life even when the brain is gone, we must also think about the right to die and the need for dignity in departing life.

Happily, my mind is still functioning, but if it should stop, I believe, I would be dead—and there would be no use in prolonging the agony. We owe it to ourselves and the ones we love to make provision for such moments. It is in the highest interest of humanitarianism that we prepared for these moments with living-will laws.

The state of New York does not have a living-will law, but Governor Cuomo is contemplating one, as is the State's Health Commissioner, Dr. David Axelrod. A Task Force on Life and the Law is considering the question, and the New York courts have already decided that when the brain is no longer functioning and there is no reasonable possibility that it will resume functioning, the individual is legally dead. The implication is that life-support technology may then be withdrawn without any question that this would be considered euthanasia.

From a legal point of view, living wills are no different from wills that leave property, appoint guardians for children and establish trusts for charity, education and research. As lawyers help people make such ordinary wills, so they should help people provide for their living and dying. The individual making the will must be of sound mind and have the capacity to express his own wishes as to the disposition of his body. These wills could also provide for the contribution, for use in transplants, of bodily organs that are no longer of any use to the individual. Lawyers should have that responsibility, too.

PRESERVE THE RIGHT TO DIE

The authority conferred by a living will must not, of course, be abused. Nothing could be more important, after all, than the right to life—and the right not to have it terminated prematurely. In the event of flagrant abuse, or any possibility of it—when a decision may seem to defy the wishes of the individual who made the will, or when loved ones are unable to determine if it should be invoked—then, of course, the patient's relatives must have recourse to the courts.

The issue of living wills is under consideration now by the American Bar Association, the American Medical Association, the Pacific Presbyterian Medical Center of San Francisco and the Committees on the Aging in both the Senate and the House of Representatives, among other organizations. We can only hope that they will all understand the need to preserve the dignity that is most precious to an older person or anyone else who has to think imminently about dying. Surely that dignity is best served by avoiding the confusion that comes from not having a will about mortality.

Short of a living will, the best way to provide that dignity is to use the durable power of attorney to appoint an individual to make medical decisions when the patient concerned is no longer competent to make them. [This is now legal in all states, although not in the District of Columbia.] Here again, the appointed person may be a relative, physician or legal or religious adviser, and here too confusion and quarrels may be avoided by conferring the necessary authority in advance.

There is, finally, the question of money, which plays a part in even this sort of decision. Many people were shocked last year when Governor Richard D. Lamm of Colorado urged people who had no real prospect of life to get out of the way and stop using resources that could be used more profitably by other people. This sounded callous, and it probably was, but it was the truth. We have not yet reached the point, even in this glorious Nation, where living or dying has nothing to do with economics. This is what makes the right to die with dignity an issue of morality as well as policy and law.

Whether we are old or young, healthy or ill, we cannot go on shirking the questions of who shall live, who shall die and who shall decide.

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Health Law

Decisions Concerning The Terminally Ill: How to Protect Patients, Staff And the Hospital

By Barbara Mishkin *

As recent events and headlines have shown, the management of a terminally ill patient can become a major problem for healthcare providers, and have a disproportionate impact on the health professionals and the institution involved. One case alone can command a significant amount of time and attention on the part of hospital administrators, incur substantial legal costs, and paralyze attending staff because of genuine concern about the legal and ethical issues involved. Yet there has been scant advice for the practitioner or administrator who wants to put sound policy into practice. This article is designed to provide some brief, practical guidance.

Although some questions remain unsettled, the basic legal principles are clear. With a few minor exceptions, competent, adult patients have a legal right to refuse medical treatment, even if such refusal may shorten their life.[1] The patient's exercise of this right may be limited only for compelling reasons (e.g., to protect the health or welfare of third parties). Moreover, the patient's refusal of life-prolonging treatment (including not only respirators but also dialysis, amputation of gangrenous limbs, and even naso-gastric feeding tubes) does not constitute suicide so long as the patient's death results from an underlying condition that is not self-inflicted.

The problem is that patients may not always have the capacity to make treatment decisions for themselves at the time a decision must be made. In that event, someone else must decide what to do. Postponing a decision is, of course, the same as making a decision either to postpone the initiation of a therapy or to continue with a given course of treatment.

As a matter of custom, healthcare providers have usually relied upon the decisions of next of kin (spouses, siblings, adult children) at least when their decisions are consonant with the physician's recommendations.[4] Some hospital bylaws or departmental rules set forth institutional policies concerning such surrogate or proxy consent. However, physicians, hospital administrators, and in-house counsel may be uneasy about relying upon the decisions of family members when their choices are not in accord with the recommended course of treatment, or when there is disagreement among the family members as to how to proceed.[5]

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The possible legal consequences are sufficient causes for concern. On the one hand, physicians have been indicted for murder as a result of withdrawing life-sustaining equipment from a comatose patient, although they believed they had the concurrence of the family to do so. An appellate court later held that their actions were taken in good faith and were not subject to criminal prosecution.[6] On the other hand, healthcare providers also have been sued for continuing a life-support system against the wishes of the patient's family and at least one appellate court has held that the institution and physicians may be held liable for damages if they persist in applying unwanted interventions.[7]

> ***"[Even a single terminally ill case] can command a significant amount of time and attention on the part of hospital administrators, incur substantial legal costs, and paralyze attending staff. . . ."***

What to Do

Given the sometimes confusing opinions as to who may make decisions on behalf of terminally ill patients, what can physicians do to protect themselves and their institutions, while also respecting their patients' wishes? There is no simple way to avoid all problems. But based on our analysis and advice to clients, I would recommend that health professionals and healthcare institutions implement at least the following steps:

TALK WITH THE PATIENT

The patient has a right to make his or her own decisions regarding healthcare, and also to insist that family members not be told or consulted about the patient's condition. Physicians commonly disregard this fact when a patient has a terminal illness. Invoking the "therapeutic privilege," they may tell the patient's spouse or adult children about the patient's illness and seek their advice concerning treatment in order to save the patient from the stress of such discussions. However, this goes against the ethical and legal principles of the patient's rights to privacy and self-determination, and related principles on which the doctrine of informed consent is founded.[8]

As discomforting to physicians as it may be, it is important to discuss possible treatment choices that may arise in the course of an illness while the patient still has the capacity to understand the implications of various alternatives, to make a reasoned choice, and to communicate that choice.

Physicians who serve as family or primary care physicians would be well advised to arrange time to discuss such matters with their patients during a routine office visit, both as a way of getting to know more about the patient's attitudes and values and as a way of encouraging the patient to consider how he or she feels about life-prolonging treatment under various circumstances. In order to avoid alarming the patient, the physician might initiate the discussion with an explanation to the effect that: "This is something I'm trying to find the time to discuss with all of my patients, because I believe it's important." This approach is far preferable to waiting for a critical event and thus alarming a sick patient by asking, out of the blue, "What would you like done if you lapse into a coma?"

DOCUMENT THESE DISCUSSIONS

This is one area in which over-documentation probably is not possible. In the office setting, it is not so important to have additional witnesses, although it might be useful to have the patient initial or sign a note describing your conversation. Even better, become familiar with legal procedures in your state for making advance directives about treatment (such as living wills), and tell your patients about the available mechanisms (see below).

If the patient is hospitalized, it is advisable to have discussions about life-prolonging treatment witnessed by another physician and a nurse—both of whom should sign a notation in the medical record affirming that the discussion was held, that the patient understood the issues presented, and that the patient made a specific treatment choice. The patient should sign the record too, if at all possible.

The importance of these procedures is illustrated by a New York case in which a court affirmed the right of a patient to terminate kidney dialysis even though the patient was comatose by the time of the court's review.[9] The court relied upon clear and convincing evidence in the patient's medical record that he had made a knowledgeable decision while he was still competent to do so. This was documented by notes and signatures of the treating physician, a disinterested witness, a nurse, the patient's brother, the assistant hospital administrator, and a psychiatrist. The evidence in the medical record was supported by the testimony of other family members and three Catholic priests, who affirmed that the patient was competent to decline the treatment at the time he made the decision to do so, that the decision was consistent with the patient's values and beliefs, and that the treatment refusal did not violate the canons of the Catholic Church.

DETERMINE THE PATIENT'S CAPACITY FOR DECISION-MAKING

If there are any doubts about the capacity of the patient to make an informed, reasoned, and voluntary treatment decision, request a psychiatric consultation and ask the consultant to be present during discussions with the patient concerning proposed treatment. Alternatively, include a separate report from the psychiatrist or psychologist in the record, preferably based upon an examination of the patient shortly before the discussions concerning proposed treatment. It is especially important to avoid the temptation to decide that a patient is incompetent because he or she has made a decision which differs from what the health professional would have decided, or which appears to be irrational. Under the law, what matters is the ability to make a reasoned choice, not the reasonableness of the particular choice that is made.[10] As then-Circuit Judge Warren Burger once observed, after reciting Brandeis' defense of the right to be let alone:

> Nothing in this utterance suggests that Justice Brandeis thought an individual possessed these rights only as to *sensible* beliefs, *valid* thoughts, *reasonable* emotions, or *well-founded* sensations. I suggest he intended to include a great many foolish, unreasonable and even absurd ideas which do not conform, such as refusing medical treatment even at great risk.[11]

Moreover, courts have held that even involuntarily hospitalized psychiatric patients, and elderly patients with marked memory impairments, are entitled to make certain decisions about their health care.[12]

IDENTIFY ALL CLOSE FAMILY MEMBERS

It is advisable to ask the relatives who have visited the patient whether there are other members of the family who ought to be consulted. It is important to know who and where such individuals are, and to contact them if possible to determine whether they agree with, or are willing to accept, the decisions made by the family representatives with whom the physician and healthcare facility have been dealing. State laws that provide authority for family members to make healthcare decisions on behalf of incapacitated patients often do not give clear guidance concerning the appropriate response when family members disagree.[13] Such situations often leave health professionals in a hopeless dilemma. Some court decisions, however, recommend seeking judicial guidance in such cases.[14]

CONSULT WITH ALL HEALTHCARE PRACTITIONERS INVOLVED IN THE PATIENT'S CARE

Make a reasonable effort to discuss the case with all of the nurses, social workers, and house staff who are in contact with the patient (including the night shift). In addition, consult with any colleagues who may be on call during periods when you are unavailable. The goal is to insure that everyone involved in the patient's care is comfortable with the proposed course of action and will implement the collective decision.

More often than not, cases go to court because a member of the healthcare team disagrees with the decisions being made and is frustrated by an inability to discuss and resolve his or her concerns within the institution.[15] The best advice for staying out of court is to discuss all aspects of the treatment decision with all interested parties, and to resolve any disagreements or qualms they may have *before* taking any decisive medical action.

INVOLVE AN ETHICS COMMITTEE IN THE DECISION-MAKING PROCESS

Many hospitals have ethics committees that can provide substantial assistance in identifying the relevant issues and resolving conflicts when difficult treatment decisions must be made.[16] Sometimes, the existence of the committee is not well known, or the procedures for bringing cases before the committee are unclear. It is useful to know in advance whether your hospital has an ethics committee and, if so, what the policies and procedures are for seeking its advice. If your institution does not have an ethics committee, recommend that one be established and that it be structured to respond quickly enough to be helpful in exigent circumstances. The American Hospital Association recommends that hospitals establish ethics committees and offers to provide information on the composition, duties and administration of such committees.[17] In addition, numerous books and articles are available that discuss the composition, administration, and operation of such committees.[18]

> ***"More often than not, cases go to court because a member of the healthcare team disagrees with the decisions being made and is frustrated by an inability to discuss and resolve his or concerns within the institution."***

LEARN ABOUT YOUR STATE'S LAW ON "LIVING WILLS" AND DURABLE POWERS OF ATTORNEY

Living Wills are documents through which individuals may direct that if they ever become terminally ill, no extraordinary, life-prolonging treatments should be employed that will merely prolong the process of dying.[19] (In a few states, living wills may be executed only *after* a diagnosis of terminal illness has been made.) Usually, these documents further direct that palliative care should be provided in order to maintain the patient's comfort, personal hygiene and dignity. State laws authorizing the use of such documents typically protect healthcare providers from civil or criminal liability as a result of good faith reliance on such a directive, and generally state that patients' treatment refusals under the terms of the statute do not constitute suicide. Fewer than half of the states recognize Living Wills, however, and uncertainties over what constitutes "terminal illness" and "extraordinary care" may render their use problematic in many cases.

A more flexible document is the "Durable Power of Attorney" through which individuals may, while competent, designate one or more persons to make decisions on their behalf in the event that they later become incapable of making such decisions for themselves. Such documents are legally valid in every state but Illinois, Rhode Island, and the District of Columbia. In some states, the laws make clear that Durable Powers of Attorney may be used specifically for healthcare decisions. In most states, however, the statute creating the Durable Power of Attorney simply provides that such powers may be either broad or specific, and apply to various subjects. Although the question has never been decided by a court, most scholars believe that a Durable Power that is created explicitly for the purpose of making healthcare decisions would be accepted and implemented, even if challenged. At a minimum, it would provide clear and convincing evidence of the individual's intentions—which is the most important factor in these cases.

> ***"[P]hysicians have been indicted for murder as a result of withdrawing life-sustaining equipment from a comatose patient, although they believed they had the concurrence of the family to do so. . ."***

Physicians and administrators should become familiar with Living Wills and Durable Powers of Attorney, and the laws governing their use, in the state(s) in which they practice. They should also educate their patients about the existence and usefulness of these documents, and have forms available for the patients to fill out, should they wish to do so, and if state law permits.

BECOME FAMILIAR WITH HOSPICES IN YOUR AREA

Hospices provide palliative care and emotional support for terminally ill patients and their families. They also provide bereavement counseling for the families following the patient's death. Families who have had the benefit of hospice care are wholeheartedly in support of the concept; however, many physicians are unfamiliar with the methods and goals of hospice care, or are unaware of its availability in their area. For patients who do not wish to receive further aggressive treatment for a terminal illness, or for whom only palliative care can be provided, a hospice offers an opportunity for the patient and the family to come to terms with the terminal illness and to help each other through the dying process. It can be a great relief to all concerned (including the primary physician and the acute care hospital) to place such patients in hospice care. Some hospices are now certified for reimbursement through Medicaid and Medicare, and many third party payers provide hospice benefits.

The steps I have suggested do not, of course, avoid the bedevilling philosophical and human problems concerning the terminally ill which often cause concern, and sometimes anguish. But these steps can help avoid legal skirmishes and stalemates that can destroy the therapeutic and caring relationship between health professionals and patients.

NOTES

1. *See, e.g., In re Conroy*, No. A-108, (Sup. Ct. N.J. Jan. [illegible], 1985), *slip opinion* at 18-33; *Bartling v. Super. Ct. L*[illegible], 2 Civil No. B007907 (Cal. Ct. App. Dec. 27, 1984); [illegible]*n F. Kennedy Memorial Hosp. v. Bludworth*, 452 So. 2d 921 (Fla. 1984); *Estate of Leach v. Shapiro*, 469 N.E.2d 1047 (Ohio 1984); *In re Hier*, 18 Mass. App. Ct. 200 (1984); *In re Colyer*, 660 P.2d 738 (Wash. 1983).

2. *Application of the President and Directors of Georgetown College*, 118 U.S. App. D.C. 80, 331 F.2d 1000, *cert. denied*, 377 U.S. 978 (1963); *cf. In re Osborne*, 294 A.2d 372 (D.C. 1972) (patient's refusal upheld).

3. *Conroy, supra*, slip op. at 59-62 (feeding tube); *Colyer, supra*, 660 P.2d at 743 (respirator); *Application of Lydia E. Hall Hosp.*, 455 N.Y.S.2d 706, 811 (Sup. Ct. Nassau Co. 1982) (dialysis); *Lane v. Candura*, 376 N.E.2d 1232, 1233 (Mass. App. Ct. 1978) (amputation); *In re Quackenbush*, 383 A.2d 785, 789 (N.J. Super. Ct. 1978) (amputation).

4. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment* (1983) (hereinafter cited as *Deciding to Forego*) at 126-132; *see also* A. Meisel & L. Kabnick, *Informed Consent to Medical Treatment: An Analysis of Recent Legislation*, 41 U. Pitt. L. Rev. 407 (1980).

5. *Deciding to Forego, supra*, at 154.

6. *Barber v. Superior Court*, 195 Cal. Rptr. 484, 147 Cal. App. 3d 1006 (Cal. Ct. App. 1983).

7. *Estate of Leach v. Shapiro, supra.*

8. S.E. Bedell & T.L. Delbanco, *Choices About Cardiopulmonary Resuscitation in the Hospital—When Do Physicians Talk With Patients?*, 310 N. Eng. J. Med. 1089 (Apr. 26, 1984), and the accompanying editorial, "Respecting the Autonomy of Competent Patients," *Id.* at 1115; *see also* President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Making Health Care Decisions* (1982) at 94-102; *Deciding to Forego* at 51.

9. *Application of Lydia E. Hall Hosp., supra.*

10. *Deciding to Forego*, at 121-124; *Conroy, supra*, slip op. at 73-75.

11. *Georgetown College, supra*, 331 F.2d at 1017 (dissenting opinion) (emphasis in original).

12. *Rogers v. Okin*, 634 F.2d 650 (1st Cir. 1980); *In re Harris*, 477 A.2d 724 (D.C. 1984); *Lane v. Candura, supra; In re Quackenbush, supra.*
13. *See generally* Meisel & Kabnick, *supra*; President's Commission, *Making Health Care Decisions, supra*, Vol. 3, Appendix L, at 206-251.
14. *See, e.g., In re L.H.R.*, 321 S.E.2d 716 (Ga. 1984); *In re Hamlin*, 689 P.2d 1372 (Wash. 1984).
15. *See, e.g., Barber, supra.*
16. R. Cranford & A.E. Doudera, *The Emergence of Institutional Ethics Committees*, Law, Med. & Health Care (Feb. 1984) at 13, *Deciding to Forego, supra* at 160-701.
17. American Hospital Association, *Guidelines: Hospital Committees on Biomedical Ethics* (approved by AHA General Council on Jan. 27, 1984).
18. R.E. Cranford & A.E. Doudera, eds., *Institutional Ethics and Health Care Decision Making* (1984); M.L. Ahern, *Biomedical Ethics Committees Confront Prickly Issues*, Hospitals (Aug. 1, 1984) at 66; R.A. McCormick, *Ethics Committees: Promise or Peril?*, 12 Law, Med. and Health Care 150 (Sept. 1984); K. Esqueda, *Hospital Ethics Committees: Four Case Studies*, 7 Hosp. Med. Staff 26 (Nov. 1978).
19. *Deciding to Forego, supra* at 136-145; *See also* N. Novak, *"Natural Death Acts" Let Patients Refuse Treatment* Hospitals (Aug. 1, 1984) at 71.
20. *Deciding to Forego, supra*, 318-387.
21. *See Deciding to Forego, supra* at 145-147; National Hospice Organization Monograph, *Decisions in Hospice* (1985 in press), Appendix C, 23-25.
22. *Deciding to Forego, supra*, at 147.
23. *See, e.g., Application of Lydia E. Hall Hosp., supra. In re Storar and Eichner*, 52 N.Y.2d 353, 438 N.Y.S.2d 266, 420 N.E.2d 64 (N.Y.), *cert. denied*, 454 U.S. 858 (1981).
24. M. Gold, *Life Support: What Families Say About Hospital, Hospice and Home Care for the Fatally Ill* (Consumers Union Foundation 1983).

The CHAIRMAN. Thank you, Senator Javits. You can be sure that this committee will give it every consideration and make the proper recommendations to the Congress of the United States.

The next witness is Dr. Edward D. Viner. Dr. Viner, you may proceed in any manner that you desire.

STATEMENT OF EDWARD D. VINER, M.D., HEAD, HEMATOLOGY/ ONCOLOGY SECTION, PENNSYLVANIA HOSPITAL; CLINICAL PROFESSOR OF MEDICINE, UNIVERSITY OF PENNSYLVANIA SCHOOL OF MEDICINE

Dr. VINER. Thank you, Mr. Chairman, members of the committee for inviting me to testify concerning this vitally important subject which is one that all of us will ultimately have to face.

I have practiced and taught internal medicine and oncology for the past 20 years and have been very much involved in the development of hospice care in the Philadelphia area. I also speak from the perspective of having been, myself, a critically ill patient. In 1972, following the resection of half of my liver, because of a tumor, fortunately benign, multiple complications led to a 4-month hospitalization, 5 weeks of which were spent on a respirator. The many invaluable lessons I learned are elaborated upon in my published article, a copy of which has been submitted to the committee. Also submitted to the committee, incidentally, is an expanded version of my remarks this morning.

We doctors really have no concept of what we ask our patients to endure, physically and emotionally. Patients would benefit immeasurably if every care provider could experience the preoperative terror of thinking he has an end-state malignancy; the nostalgia inherent in believing he will not see his children grow up; and the preterminal mourning over the thought that he is leaving behind everyone that he knows and loves. It is really too bad that every doctor and nurse has not experienced an intensive care unit psychosis and the state of complete physical and emotional exhaustion that ultimately reduces even the strongest patient to a lip-quivering, eye-watering mass of protoplasm.

The particular facts of my personal illness have no relevancy except to underscore the generic philosophical issues raised by them. One of the most important of these is for whom is this type of heroic care appropriate. As I lay there on the respirator, I thought often of how wrong all that I was being put through would have been if, indeed, my liver tumor had been malignant and inoperable.

My experience as a patient has helped me to be a better doctor in a number of basic ways. I hope and trust that I now find it easier to listen to my patients' wishes and feelings. I no longer use machines and other intensive supporting procedures simply because they exist. And I can accept comfort as an end in itself. I am better able to deal with the realities of life which dictate that some patients should be allowed to die quietly, with dignity, without stress, and without machines.

Having come away from my ordeal with these various perceptions, I struggled with the issue of what practically speaking could be done to improve institutional dying. Clearly, the concepts inherent in the hospice approach, which was just being introduced in the United States at that time, were in concert with my own reflections while on the respirator.

What is hospice? Hospice in the United States is not a place, but a philosophy of care with an interdisciplinary team working together to provide palliative and supportive care to meet the specific physical, emotional, spiritual, and social needs that arise in the dying patient and his family. It is important to stress that the hospice concept does not imply the cessation of care. Rather, it forces us to define those theraupeutic goals appropriate for that patient, and then to substitute sensitive and personal support from machines, chemotherapy, and antibiotics.

Unfortunately, while the idealistic goals of hospice care are clearly worthy, we have not yet figured out how to pay for it. And one of the greatest tragedies is that the Medicare legislation has imposed such limitations on hospice benefits, that most patients and programs alike regard the Medicare provisions as a negative. Patients now basically have to choose whether to retain their traditionally available medical benefits, or elect very limited hospice benefits, which choice requires relinquishing coverage for all other forms of medical care. Thus, instead of relieving the pressure on the elderly, this choice only intensifies it. Also, the present legislation carries with it the potential of bankrupting those high quality hospice programs which really do feel an ethical commitment to the terminally ill.

Accordingly, we at Pennsylvania Hospital, as have so many other programs, have chosen not to adopt the Medicare model. In short, the present regulations have given us half a loaf which, in this case, may be worth less than nothing.

What we working in the field want, as no doubt do you legislators representing the consumer/patient, is preservation of the options and the individualization of service. Hospice may well not be the only answer, but it is one whose precepts can coincide with these goals. Now is the time for innovation and experimentation with hospice care and other comprehensive services for the ill and dying. Ultimately, we must integrate these concepts into the health systems in the United States and develop stable patterns of funding, staffing, and regulation.

There are other areas in which we should also be working. Each of us, individually, must identify and redefine attitudes and feelings about critical illness, dying, and death. Collectively, we must continue to foster the evolution and societal thinking that is resulting in a climate today that increasingly allows quiet, private decision making by the patient, his family, and his physician. Hopefully, we will never see another travesty such as the Karen Ann Quinlan case. We must continue to educate our young physicians concerning the special needs of the aging and dying. We need to encourage more patients to take advantage of such mechanisms as living wills and durable powers-of-attorney, as Senator Javits mentioned; and, at the same time, we must create laws which will allow these mechanisms to be meaningful.

In closing, I plead with you, members of the Government, that in our effort to contain costs, we do not decimate the resources that should be available to the dying patient. Let us ponder the sobering

reflection that one day, all of these overwhelming problems will confront each of us. Just what do we want for ourselves and for our loved ones? Thank you.

[The prepared statement of Dr. Viner follows:]

PREPARED STATEMENT OF EDWARD D. VINER, M.D., HEAD, HEMATOLOGY/ONCOLOGY SECTION, PENNSYLVANIA HOSPITAL; CLINICAL PROFESSOR OF MEDICINE, UNIVERSITY OF PENNSYLVANIA, SCHOOL OF MEDICINE

Thank you, Mr. Chairman, and members of the committee, for inviting me to testify concerning this vitally important subject, which is one all of us ultimately have to face.

My perspective reflects a 20 year experience practicing and teaching internal medicine and oncology. For the last decade, I have been very much involved with the development of hospice care in the Philadelphia areas. Lastly, I also speak from the perspective of having been, myself, a critically ill patient, who, in 1972, spent five weeks on a respirator, and four months in the hospital. The many invaluable lessons I learned are elaborated upon in my article, "Life at the Other End of the Endotracheal Tube. A Physician's Personal View of Critical Illness," a copy of which has been submitted to the committee.

Briefly, we doctors really have no concept of that which we ask our patients to endure, physically and emotionally, all at a time that they are most vulnerable, physically and emotionally. Patients would benefit immeasurably if every care provider could experience, as I did, the preoperative terror of thinking he has an end-stage malignancy, the nostalgia inherent in believing he will not see his children grow up, and the preterminal mourning over the thought that he is leaving behind everyone whom he knows and loves. It really is too bad that every doctor and nurse has not experienced an intensive care unit psychosis, and the state of complete emotional and physical exhaustion that ultimately reduces even the strongest patient to a lip-quivering, eye-watering mass of protoplasm.

The patient lives in a very circumscribed world. Accordingly, everyone who enters his day assumes a magnified role. That person's single most important attribute is whether he or she really cares, a quality which the patient is uncannily able to perceive. It is imperative that we remember to listen to our patients, to their symptoms, feelings, attitudes and wishes concerning their care. The thought of dying became a most pervading and relentless issue, and my own autopsy was the subject of an incessantly recurring nightmare. Ultimately though, I became quite ambivalent, and comfort became far more important than a few more days or weeks of life. At times, I had great need to ventilate concerning these anxieties, and honest discussions of my plight, with my surgeon, were immensely helpful. I learned that it is imperative that we overcome the longstanding conspiracy of silence and avoidance with respect to death, and that we must bring these aspects up for discussion with patients who are obviously seriously ill. Such interchanges need not imply that there is no hope, but where there is none, I learned that it clearly is preferable to discuss the issue rather than evade it.

The particular facts of my illness have no relevance, expect to underscore the generic philosophical issues raised by them. One of the most important of these is for whom is this type of heroic care appropriate? Unless someone drops dead on the golf course, he will be admitted to the hospital and subjected to a tremendous array of procedures and treatments before he is allowed to die. While I am, of course, grateful to have survived, it is also clear that the patient pays dearly in such a circumstance. Most pertinently, I lay there often thinking of how inappropriate all that I was being put through would have been, if indeed, I had had an incurable terminal illness. I became angry at the neurosurgeons caring for the patient next to me. It was apparent that they were inappropriately administering the same kind of heroic care that I was getting to an unfortunate man with an inoperable, highly malignant brain tumor. Only I knew how much he was suffering because my fellow physicians had to assuage their own feelings of impotency.

There is a risk that my comments may be misunderstood. I am not advocating that doctors should run around playing God, turning machines off. At the same time we physicians cannot avoid the issues. We must try harder to define just what are the practically achievable and appropriate goals for the care of each individual patient. Cesssation of an aggressive approach does not mean cessation of intensive care. It does involve substitution of comfort for the patient, and sensitive support for both the patient and the family, in the place of more machines and other technology.

My experience as a patient has helped has me to be a better doctor in a number of basic ways. I hope, and trust, that I now find it easier to listen to patients. I no longer use machines, and other intensive supportive procedures, simply because they exist. I can recognize that the patient should be the beneficiary of what we are doing and not the victim. I am able to talk more easily with sick people, now that I have been there, and I understand that these patients are preoccupied with the fear of dying, and want to talk about it. I am more liberal with the use of morphine when indicated, and can accept comfort as an end in itself. In short, I am able to deal better with the realities of life, which dictate that some patients should be allowed to die quietly, with dignity, without stress and without machines.

Having come away from my ordeal with these various perceptions, I struggled with the issue of what practically could be done to improve institutional dying. Clearly, the concepts inherent in the hospice approach just being introduced in the United States in 1972, were in concert with my own reflections while on the respirator.

What is hospice? The word hospice means a place of refuge for travelers, like the words hospitality, and hospital, it stems from the Latin word, "hospes," which can mean host or guest. Today, the word hospice has a new meaning that remains true to its origins. It now refers to a way of caring for people nearing the end of their journey through life, who are faced with dying, and who are indeed in need of refuge. While in England it refers to a special place, i.e., a literal refuge, in America it connotes a philosophy of care, and a stem of individuals working together to provide comprehensive management. Such a team is recruited from many disciplines including the clergy, medicine, nursing, social work, the allied health professions, and very importantly, lay volunteers. The hospice philosophy seeks to restore dignity and a sense of personal fulfillment to the dying. The hospice team provides palliative and supportive care to meet the special physical, emotional, spiritual, and social needs that arise for both the patient and family during the final stages of illness, and in bereavement. Hospice care implies a continuum of appropriate institutional, and more importantly, home care, available 24 hours a day, seven days a week. The focus is on the patient, and the family, rather than on the disease. The aim is not to extend life, but to improve the quality of the life that remains.

Introduction of the modern hospice implies the question, "Why is it necessary?" Who among health professionals, would not want the dying to benefit from compassionate, unhurried, supportive care? Who would willingly deprive the dying patient of dignity or peace of mind?

However, the dying patient presents a great dilemma for the physician. We are equipped with a vast armamentarium of drugs and devices to fight the battle for life. The world armamentarium is deliberately chosen to describe the forces at the common of the health professional. The image of a war against death is intentional. When it occurs, death is tantamount to defeat, and the medical staff the humiliation of failure. Before yielding to defeat, therefore, the health professional finds it difficult to resist bringing to bear the incredible array of esoteric diagnositic tools, exotic drugs, and electronic and mechanical devices available for extending life. As the limits of survival approach, the medical team is so personnaly committed to the success of their efforts that even more is done to try to help the patient. The latter too often becomes a dehumanized, biomedical subject caught in a vicious circle. Ultimately, the accomplished feat is postponing death rather than prolonging life. Indeed, the distinction between life and death is now so nebulous that an acceptable definition of death is still debated in medical/legal circles. Gone are the days when a patient was dead simply because breathing stopped. In fact, now house officers seem to feel an obligation, because of an unfortunate misapplication of coronary care unit procedures, to ask families, and even patients if they are conscious, whether they want an attempt at resuscitation when the patient's heart stops-as if we could "undie" the patient by this maneuver.

We cannot blame the health professional alone for this situation. The doctor is caught between the technical, legal and moral issues and the ambivalence of society. As Elisabeth Kubler-Ross pointed out a number of years ago, we had become a death denying society. Not only physicians and nurses, but lay persons too, felt compelled to fight death at all costs. Often, even if the physician was ready to stop aggressive therapy, the patient's family pressed for one last "goal-line stand." In the past decade, however, both physicians and laymen began to recognize that the patient might become the victim of the applied technology. This led to a profliferation of articles and books in both the medical and lay press about death and dying. The subject became a popular one for television programs, public debates, and church group discussions. Importantly, these issues began to be included in the curriculum of medical schools, for it simply imperative that we sensitize and educate young physicians in this area. Quite suddenly, we realized a need to examine whether we were using our tools properly, or whether we were departing from the best interests of the patient. We began to question our practices, not only medicially and scientifically, but also from the economic, legal, moral, and human points of view.

Over the last few years, attitudes have changed so that more, but unfortunately by no means all, physicians feel it is no longer absolutely necessary to use every weapon in the medical armamentarium. We have much less pressure from families, who today, more often than not, are realistically asking doctors to stop aggressive therapy when it has no possible benefit. We have progressed to the point where it is thought ethically appropriate to withhold chemotherapy that may do more harm than good to the end-stage patient, and to abstain from the use of antibiotics when penumonia would provide a peaceful and welcome end to a prolonged battle with cancer. More physicians are becoming aware that legally, a physician must only do that which is "right" for his patient and that does not necessarily mean more technology. We doctors are learning that we have a legal duty to discuss the prognosis and treatment alternatives with the dying patient, just as with the non-terminal patient, and that both patients have the same right to accept or reject treatment. The concepts of the living will and the durable power of attorney, whereby a person may appoint a surrogate to carry out his intent in making health care decisions after he is disabled, have been helpful.

Certainly, this re-evaluation of death and dying in the United States was a prerequisite for the implementation of the hospice philosophy. It is important to reiterate that the hospice concept does not imply cessation of care, but rather the substitution of proper care for the terminally ill patient. In short, it means appropriate, sensitive, and personal support, instead of machines, chemotherapy, and antibiotics.

In starting our hospice program at the Pennsylvania Hospital in Philadelphia, we were, at first, disappointed that there was no way to fund a separate hospice facility similar to those that existed in England. We were forced by economic necessity to integrate hospice activities into the general hospital setting. However, this approach proved to yield several important advantages. Hospice care is really good medicine, in the fullest sense of the term. Our hospice team, functioning in the general hospital environment, had a clear-cut ripple effect which disseminated the philosophy, idealism, and sensitivity of the hospice approach to affect care generally throughout the hospital. We were particularly pleased with the interest and enthusiasm of the ordinarily technologically oriented nurses, medical students and house officers and the latter make regular home visits with the hospice nurses.

From the beginning, one of our major goals was to get our patients home as quickly as possible, a concept desirable both from the economic and humanitarian points of view. However, it is imperative that economic pressure to discharge patients quickly not interfere with proper preparation nor be allowed to prevent necessary readmissions. In Philadelphia, we collaborate with already established community nursing services to provide at home the comprehensive support inherent in the hospice concept. The advantages for the patient of dying at home, as compared with institutional dying, are obvious, but there is also an obvious need for security on the part of the families—security that stems from knowing that help is continuously available in the event of one of the myriad of crisis situations that can, and do occur. This security has greatly decreased the number of readmissions precipitated by understandable patient and family panic over such symptoms as coughing, vomiting, unremitting pain, and emotional decompensation, and has allowed an increasing percentage of our patients to die peacefully at home. At the same time, however, it is important that neither economic pressure, nor over enthustiastic advocacy for home care be allowed to inflict on patients or families a sense of failure should readmission be necessary.

Unfortunately, while the idealistic goals of hospice care have now been recognized to be eminently worthy we have, as a society, not yet figured out how to pay for it. Let us look at the realities of what has happened. Concerned about the needs of terminally ill patients and their families, California Congressman Leon Panetta originally introduced legislation designed to ease access to hospice programs for Medicare recipients. Unfortunately, this humanistic motivation ultimately gave way to cost control requirements. As a result, very tragically, instead of hospice providing relief of the pressures on elderly and non-elderly dying patients, a new conflict has been added. Patients now basically have to choose whether they will retain their traditionally available medical benefits, which include essentially no payment for most hospice services, or elect very limited hospice benefits, which requires relinquishing coverage for other forms of medical care. The potential loss of all Medicare benefits is neither psychologically nor medically appropriate. Medicare requirements pose a problem also for the hospice program. Ideally, such programs should be designed to meet needs of the local community. Responsiveness to patient's and family's needs should take priority. However Medicare requires us to fit the government's model and in the end we have just substituted another bureaucratic entity for the regimentation of ordinary hospital life that we are trying to circumvent.

It has been surprisingly hard to prove that which seems self-evident, i.e., that hospice type care indeed offers a true saving. Problems with the various studies include design difficulties, and the great variability of hospice programs, some comparing less favorably than others on cost issues becaue of greater use of hospital in-patient days. Also, many of the evaluations of the cost of conventional care are based on insurance claim forms, and do not take into account the true total cost based on patient experience. Currently, the preponderance of recent studies suggest that hospice type care may produce a relative saving of about 40%. Irrespectively, in the end, it it is better, hospice care should still be regarded as justifiable, as long as it does not cost more.

There are many unanswered questions, in addition to the paramount one concerning funding. These include the definition of what consitutes proper hospice care, the establishment of criteria for patient selection, and the determination of the best model or models for our country. All should be reminded that a hospice can't be created by simply hanging a sign over a nursing home door. A hospice can only be as good as its foundation, its planning, and its people, and it takes months, or years of painstaking work to define specific goals, set up operational guidelines, educate the local medical community and to assemble an effective staff.

In espousing hospice care as an important potential solution to the conflicting pressures on the dying patient, it is important to reflect on these stresses. The dying patient needs to know of available resources, and how best to muster them. He needs information about treatment and help with decisions concerning treatment. He will do best with an accurate and honest appraisal of hope versus reality. He needs help during the period of transition between denial and the onset of realistic planning.

The dying patient is concerned with the adequacy of his financial coverage, for both his acute and palliative care, and about the additional financial burdens that may be inflicted on his family by debts, or loss of income. The dying patient needs enough physical, emotional and financial support to enable him and his family to use the remaining time as fully and profitably as possible. He needs assurance that he won't be alone, and that his family won't be crushed by the responsibility of caring for him.

While he needs a type of care and emphasis not found in the acute care system of our hospitals, he nonetheless needs to be able to stay under the care of his physician and he needs the availability of the acute care system to provide help in certain specific circumstances, and to serve as a link with hope. Note that it is this availability that is denied by the current Medicare approach to hospice care. As the loved one is dying, great pressure is put on families as well. They, too, have much need for information concerning resources, and for help in learning how to support and care for the patient. Both patient and family need supplies, home-making and nursing help, and a caring and supportive physician who is comfortable with what is his ultimate role in the care of every patient, i.e., that of helping him die. Physicians and other care providers in turn need information about the patient and family's attitudes and feelings, and about the home and financial situation. They also, themselves, need help and support with the difficult job of working with patients with terminal illness.

Yet, while we have learned that the hospice approach has the potential for filling all of these needs and for alleviating many of the conflicting pressures, it finds itself in conflict with the recent push to make our health care more "cost effective." Even if hospice care really is cheaper, that is no longer enough. Originally, the assumption was made that the cost of dying would be less if decisions were made to decelerate, or end acute care therapy. This assumption fit with the legislative thrust to cut the cost of health care, and soon dying was on the trajectory of low cost care. The next step was to see home care as cheaper than hospital care, so the quicker and cleaner the break with the acute care system, as demanded by current Medicare regulations, the better. Indeed, according to the Health Care Financing Administration, the "goal of hospice care is to help terminally ill individuals continue life with minimal disruption of their normal activities, while remaining primarily in the home environment." However, the goal of hospice care should be "appropriate therapy" that may or may not be at home. The hospice pioneers wanted home to be a viable option, but not the only option, for the transition from acute to palliation cannot be that precise. It is imperative, both psychologically and practically, that dying patients retain all their options for treatment. They need time to accept the transition, and they need to retain their affiliation with their doctor and their hospital. After the transition, which may take days or months, home care can then be emphasized and can be less expensive.

However, home care is confronted with two challenges. Technology is being transferred from the hospital to home care, and as a result, the choices concerning the use of this technology become even more complicated. Also Medicare, and the other insurers will follow, is imposing an increasing burden on home care providers to assess, document and evaluate, thus incrseasing paper work and forcing cuts in services. Medicare is also putting increasing pressures on the families providing the home care, for the increassed technology coupled with DRG engendered earlier discharges, require increasingly skilled supervision. Thus decisions concerning treatment are increasingly complicated, even when the goal is palliation and it is carried out at home. At a time in the patient's life when humanistic concerns demand easier decision making and less pressure, another force is demanding low cost care. Simultaneously, the regulatory agencies are more and more distrustful of the professionals' ability to deliver quality care. In the meatime, patients and families are plugging along, carrying ever bigger burdens, feeling that somehow they are doing something wrong, because everything is so complicated, expensive and difficult, while all the time the experts are telling them it's getting better.

The change in emphasis on hospice as potentially cost-saving, to hospice at the lowest possible cost, threatens to destroy the qualitative difference that is hospice. The press for "cost containment at any cost" brings with it the danger of less than adequately prepared individuals providing care in less than adequate circumstances. The present legislation imposes a devastating amount of paper work and also carries with it the potential for bankrupting those high quality hospice programs with ethical commitments to the terminally ill. There is a built-in incentive to take patients only at the very end, so their sixty-five hundred dollar cap will see them through. Programs tend to protect themselves by rejecting those patients who have the greatest need, i.e. those who have no primary care giver. This legislation has given us half a loaf, which in this care may be worth less than nothing.

Because the issues and systems are so overwhelming, patients and families need help. Programs such as hospice guide them throughout the process. What we working in the field want, as no doubt do you legislators representing the consumer/patient, is preservation of the options and the individualization of service. Hospice may well not be the only answer, but it is the one whose precepts coincide with these goals. Now is the time for innovation and experimentation with hospice care and other comprehensive services for the ill and dying. Ultimately, we must integrate the concept into the United States health system and develop stable patterns of funding, staffing, and regulation.

There are other areas in which we should be working. Each of us as individuals must identify and redefine attitudes and feelings about critical illness, dying and death. Collectively, we must continue to foster the evolution in societal thinking that is resulting in a climate today that increasingly allows quiet, private decision making by the patient, his family and his physician. Hopefully we will never see another travesty such as the Karen Ann Quinlan case. We must continue to educate our young physicians concerning the special needs of the aging and dying. We need to encourage more patients to take advantage of such mechanisms as Living Wills and Durable Powers of Attorney, and at the same time, create laws which allow them to be effective.

In closing, I plead with you members of the government that in our effort to contain cost, we not decimate the resources that should be available to the dying patient. Let us ponder the sobering reflection that one day, all of these overwhelming problems will confront us. Just what to we want for ourselves and our loved ones?

The CHAIRMAN. Thank you, Dr. Viner.

I would like to start out the questioning, first of all, to Senator Javits, and then give each member of the panel an opportunity to ask one question, and then we will come back again for more questioning.

I would like to, first of all, establish the difference between a living will and a durable power of attorney.

Senator JAVITS. A living will is a direct expression of the attitude of the maker of the will toward the disposition of his own body when he is no longer competent to decide; and when there is medically no probable likelihood of recovery. It is a testamentary document. And, as I said in my remarks, it is not irrevocable, but it is a very definite guide to those who must decide for him because he cannot decide himself.

The durable power of attorney is a devolution of authority to another to make any medical decision for the maker of the durable power. And it is durable because, again, it is irrevocable except by courts and after clear and convincing proof.

Now, at this point, Mr. Chairman, I think it would be helpful if Ms. Mishkin was given a few minutes to give you some of the distinctions as follows. The laws of different States give different authorities to the profession, the medical profession, and to the families of the afflicted. And these are important distinctions, as they may be a guide to national policy.

So if the Chair is agreeable, please give Ms. Mishkin a few moments.

The CHAIRMAN. Ms. Mishkin, you are now recognized.

Ms. MISHKIN. I will respond directly to the question you posed. A very important distinction between a living will and a durable power of attorney is the that application of the living will is limited. It applies only to people who have been diagnosed as terminally ill, and would not apply to many of the very elderly people in this country who are simply getting older, older with more of their systems failing, with an uncertain prognosis and with an unknown length of life remaining.

A living will would be of no use to an elderly person in a nursing home unless that person happened to be diagnosed as clearly having a terminal illness. In addition, a living will is not valid in all of the States. I will submit for the committee a list of the States in which it is not valid.

[The following information was subsequently provided by Ms. Mishkin:]

STATES HAVING NO NATURAL DEATH ACT

Alaska, Hawaii, Kentucky, Massachusetts, Michigan, Minnesota, Nebraska, New Jersey, New York, North Dakota, Ohio, Pennsylvania, Rhode Island, South Carolina, and South Dakota.

Ms. MISHKIN. In addition, certain procedural requirements in living wills vary from one State to another, so that it is not clear what would happen to an individual who executed a valid living will in one State and then found himself or herself hospitalized in another State, if the two States required different formalities to execute a living will.

There are also definitional problems with living wills. The physician or health care provider must decide whether a proposed intervention is extraordinary care—which may be withheld or withdrawn according to the directions of the living will—or whether an intervention is supportive or palliative care, administered to maintain the patient's comfort and dignity through the dying process. There is great consternation now and difficulty in deciding whether or not providing nourishment and hydration through artificial means, such as a nasogastric feeding tube or an intravenous solution, would constitute extraordinary care that may be withheld, if appropriate; or whether it is nursing care that must under all conditions be provided.

Roughly a dozen States that have passed living will legislation in the last year have incorporated a provision specifying that artificial nourishment and hydration must be provided, that they do not constitute extraordinary care that may be withheld or withdrawn from a terminally ill patient.

Finally, the most important distinction between a living will and a durable power of attorney, of course, is that the living will is only useful for people who want to say no. It is only useful for the person who does not want extraordinary care continued. Now, there are many people who might feel otherwise, and there are many people who might want certain kinds of extraordinary care provided and other kinds withheld. It is a very personal decision. A living will is not helpful for those situations. But a durable power of attorney, whereby you or I or—anyone else—can give authority to someone else to make health care decisions for us, means that we then have a spokesperson who will answer the question about nutritional support or other interventions at the time the question arises, based upon our medical condition at that time. It means that if I want all systems go or if I want everything possible to be done to preserve my life, I can have a spokesperson there who will see to it as vigorously as possible—that it is done. The spokesperson similarly would see to it that nothing is done, if that's what I prefer.

Durable simply means that the power-of-attorney does not evaporate when the person who delegates the power becomes incapacitated. Under prior law, if you were no longer competent, a power-of-attorney would become void.

The new laws make it possible for the power-of-attorney to continue in effect even when your competency does not.

The **Chairman**. Thank you, Ms. Mishkin.

The Chairman recognizes Mr. Henry.

Mr. **Henry**. Thank you, Mr. Chairman.

I really wanted just to follow up on this because I think it is an extremely important distinction, and it has also been very helpful to me in making the distinction between the living will and the durable power-of-attorney. I am from Michigan, where we have the latter, not the former. I note the Senator from New York, the distinguished doctor from Pennsylvania, all three of us are States that do not presently allow for living wills. We do allow for the durable power-of-attorney.

The living will is more clearly self-directed, although more clearly legislatively circumscribed. The power-of-durable-attorney is a broader grant of power.

Is there a distinction between the interstate recognition on power-of-attorney as opposed to living will? That is to say, we have many problems, of course, with senior citizens who live—well, in all of our areas that are represented at the witness table, who tend to prefer, for example, warmer climates in the winter; and many problems in terms of getting interstate recognition.

I am wondering whether there has been a clear distinction in terms of which the courts have found more easily to get reciprocity; and, second, related to that, whether you feel there is a need for some kind of model national statute that would bring greater uniformity in this area to deal with the areas where problems have occurred.

Senator JAVITS. Ms. Mishkin should probably reply on the case law. As for me, I am very strongly for a national model. We have enough trouble with this whole subject without having a jurisdictional problem and conflict.

Ms. Mishin, would you help us with the case law?

Ms. MISHKIN. Yes. There has not yet been any court decision with respect to a durable power-of-attorney, drafted and legally valid in one State, being put into effect in another. The same is true of the living wills.

Generally, the durable power-of-attorney statutes are much more compatible with each other so that transfer from one State to another should not be too difficult. On the other hand, there are roughly half a dozen States that do require special procedures for creating a valid durable power-of-attorney. They may require that it be recorded with the Recorder of Wills or the Office of the Clerk of the Court. This is a holdover from the days when powers-of-attorney statutes were part of the property law. In fact, they still are, or they are part of the wills and trusts code. Therefore, some of the States—a very small handful—do have additional requirements. As a result, someone who created a durable power-of-attorney, in a State that doesn't have those additional requirements, might have difficulty implementing it in a State where those requirements are in effect. There is no case law as yet.

Senator JAVITS. May I simply add, Mr. Chairman, that whatever may be the legal problems, the fact that an individual who has expressed his will on this subject or appointed a surrogate under a power to express that will through a durable power-of-attorney will immediately establish a standard for that person, which will help materially to reduce, on the one hand, the confusion about ascertaining the will of the person facing death; and, on the other hand, relieve the medical profession to some extent, I think substantially, of getting into the morass of liability which is so difficult, as the chairman said originally today.

So I definitely believe a big step will come from the national model to induce people generally to express their will on this subject as casually and usually as they make a will for property.

The CHAIRMAN. The gentleman's time has expired.

May I state that the committee will recess very briefly. But before we do that, I would like to thank Senator Javits, Dr. Viner, and Ms. Mishkin for their excellent testimony.

We will return to continue the questioning in approximately 60 seconds.

Thank you very much.

[Recess.]

The CHAIRMAN. The Committee will continue its sitting, and will now recognize Ms. Lloyd.

Ms. LLOYD. Thank you, Mr. Chairman.

I want to commend you and thank you for holding this hearing on a matter that does affect so many of our older citizens. And I certainly want to thank Senator Javits for being here today to give us the benefit of his expertise.

All of us know that dying is an inevitable part of life; that where there is a beginning, there has to be an end. And I do not think that any of us expect to avoid it. But if we had our choice, I think that all of us here would like to go out of this world in a very painless and a very dignified state. Unfortunately, this choice is denied to many of us.

Along with older age, there is increased risk of crippling and very painful diseases, diseases that debilitate the body, the spirit and, all too often, the pocketbook. It is this latter that often controls and limits the options available to us insofar as health care, custodial care, and even the final formalities of a funeral are concerned.

I believe that everyone is entitled to affordable, compassionate, and competent care. I also believe that the Government has responsibility to shape its programs so that our older people who do have a terminal disease can choose how they want to spend their final days here on this Earth. And, certainly, that is what this hearing, "Dying With Dignity: Difficult Times, Difficult Choice" is all about.

Thank you, Mr. Chairman, for letting us have this hearing today.

The CHAIRMAN. Thank you.

The Chair recognizes Mr. Wortley.

Mr. WORTLEY. Thank you, Mr. Chairman.

Senator Javits, in your testimony a few moments ago, you mentioned abuses of living wills and that they could be restrained by the courts, and you alluded to the litigious society we live in.

Do you foresee any legal problems with living wills or durable powers-of-attorney? Might we be overburdening the courts with such cases, or are we consigning, perhaps, too much power to the court to make decisions in our lives?

Senator JAVITS. Well, Congressman, I do not think, to answer the second part first, we are giving the courts too much power. They have had that kind of power for the duration of our Republic and our appellate procedures and other safeguards. I think it has kept us out of deep trouble.

We are a litigious society. Our courts are very heavily burdened. But I think the compensation is that we will be reducing their burdens if people can evidence in a binding way their own desires. And I do not think we will be increasing the totality of litigation.

In addition, finality is critical here for those who are in the medical profession and for people who are facing these awesome decisions themselves. So I do not consider our court congestion an obstacle. I rather think that we will be lessening rather than increasing it.

Mr. WORTLEY. I wonder if I could ask Counselor Mishkin, What do you think the alternatives are if all States do not adopt the living will statute?

Ms. MISHKIN. Well, the alternatives are clearly more litigation. One of the problems we have now is that despite the tradition that a spouse or an adult child has authority to make health care decisions for an incapacitated adult, in fact, their authority to do so is clear in only about a dozen States. In all of the other States, there is no clear legal authority for a spouse or an adult child—or a brother or sister or any family member—to make a health care decision on behalf of an ill on an incapacitated adult. So we are faced with uncertainty on the part of the health care providers—the hospital, the hospice, the nursing home—as to whether or not to follow the directions given by a family member. And whenever they are uneasy about that which the family member requests be done or not done, they will go to court. That is the alternative that these documents are designed to avoid. Going into court is time consuming. Normally, it does not even help the patient in question because the patient typically dies before the court renders its decision. It may help subsequent patients.

In addition, it is demeaning to the patient to have to go to court and to have an incompetency proceeding and guardian appointed. Unfortunately, that is the only alternative we have right now, until more people sign these documents.

The **Chairman**. The gentleman's time has expired.

Mr. **Wortley**. Thank you, Mr. Chairman.

The **Chairman**. The Chair now recognizes Mr. Vento.

Mr. Vento, it has been decided to ask one question per member.

Mr. **Vento**. Thank you, Mr. Chairman.

I do not have a great deal to question the distinguished Senator. Now I think that much he reflects, as our own late, great friend, Hubert Humphrey, who he worked so well with in the U.S. Senate, from our State of Minnesota, we are so proud that you are still in the vanguard leading the way, attempting to bring a light on the public policy path that we have to follow with regard to health care and to this very sensitive issue.

It is so hard for us, obviously. No one can speak with authority unless he has been there, unless he is experiencing it. And this, I am sure, will be an important catalyst as we attempt to develop public policy in Congress with regard to this issue.

And the real problem today, Senator, if I might say, is the fact that not only are we pulling back in some programs because they have problems, but we are not out there leading the way with the new programs, whether it is the hospice, whether it is chemical dependency problems for the elderly, whether it is many other problems. And I am not so concerned about trying to repair the transgressions and imperfections of programs. After all, that is part of the public process that we are all involved in in terms of trying to—the competition of good ideas and trying to promote those.

But what I am most concerned about is that we are not replacing them and addressing what are sincerely the concerns of the 1980's.

I am happy to note that we can make hospitals the last resort in terms of—but we have to have an appropriate type of health care. I think that is the message. And we have to have appropriate care for people. We do what we can for their health, but then we have to deal with the psychological effects and all the other problems that are inherent in life and in the process of death.

So we are very grateful for your shedding light on this, and I think and hope it will be a catalyst so we can address these concerns in a positive manner in the future. And we are grateful for it. I want to commend the chairman for his calling this hearing today.

The **Chairman**. Thank you, Mr. Vento.

The Chair now recognizes Mr. Falwell.

Mr. FALWELL. My question could be directed to either of the witnesses.

We have delved primarily upon those instances where people can evidence, hopefully in a binding way, their decision, in using the living will or the durable power-of-attorney. Hopefully, we have some good chance of a binding decision being recognized.

Mention was made of the Quinlan case. For most of us, who have not executed such living wills or durable powers-of-attorney, what can we do in trying to delegate others by means of the law to make those binding decisions? You talked about the National Model Law. Won't that be extremely controversial?

Senator JAVITS. My judgment is that the one law in all the 50 States will be helpful, and public education which we are engaged in right now, thanks to you Chairman Roybal, is very helpful. And it may be possible to construct a national model statute; then to enlist the Bar Association and other similar agencies representing the people to make this a bandwagon effort. It has just begun.

Senators had a symposium under the jurisdiction of the Aging Committee and this has now occurred in the House.

I yield to Ms. Mishkin.

Ms. MISHKIN. Thank you, Senator.

I did want the record to reflect the fact that model laws have been approved by the Commissioners on Uniform State Laws: One involving health care consent, which would provide legal authority for family members to consent to health care on behalf of adults; and another on rights of the terminally ill. I will provide copies of those model laws for your record.

[See appendix 4 for material submitted by Ms. Mishkin.]

Dr. VINER. The problem in the Quinlan case—and I know Mrs. Quinlan—was that the hospital and the physicians involved would not respect the wishes of the family and were afraid that medical/legal issues would preclude their safety in doing that. In most cases, this is very simply and quietly, laws available or no laws available, we make those decisions every day because we have to, and there is no fanfare, no fuss, no publicity, and it is quiet and it is private. And it is getting easier because societal thinking is changing. Half a dozen—more than that—10 years ago, you usually got the family requesting one last goal line stand, and there was always to be another one. And today, more and more, that is no longer the case. Families are willing to give up sooner; do not want to see loved ones subjected to becoming biomedical subjects and so forth. We are much less often getting that pressure. We are quietly making these decisions.

The public education that Senator Javits talked about is extremely important. That is how the evolution is taking place. That is how it will further take place.

The CHAIRMAN. The Chair recognizes Mr. Biaggi.

Mr. BIAGGI. Thank you, Mr. Chairman. I apologize for being late. I was at another committee, marking up an important bill.

I would like to take this occasion to say hello to an old and dear friend, respected, revered, and loved man that I have worked with in the Congress on legislation, Senator Jack Javits.

I recall—and you may not remember, and I was a little younger, I was a letter carrier on the west side when you had the temerity, the audacity to run for Congress as a Republican on the West Side of Manhattan. And you showed the way. The store keepers were telling me, he is the only candidate that ever came and opened the doors and greeted us. Many have followed that pattern and have proved to be successful, as you were. But, more than that, you continued on to fight for people while you were a Member of the Senate. And those were heroic fights because oft times you were alone. But time and events and experience certainly confirmed the fact that you were correct.

You are to be admired even more greatly now. My respect for you has no bounds. It grieved me when you left the Senate. It pleases me to see you go on dauntlessly and indefatiguably in your life's commitment to helping human beings. Your courage is inspirational.

Jack, it is a delight to see you.

Senator JAVITS. Thank you, Congressman. As you said, you are an old and dear friend. It makes my continuance in an active life a very rewarding one. Thank you very much.

And while I've got the floor for a minute, I would like to thank Congressman Vento, too, for invoking the name of one of my heroes, Hubert Humphrey, whose spirit must be hovering over us right now.

Thank you very much.

Mr. BIAGGI. Thank you, Senator.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you.

The Chair recognizes Mr. Boehlert.

Mr. BOEHLERT. Thank you, Mr. Chairman.

All three of the panelists have given us a lot of food for thought. It is going to take me some time to adequately digest it. But I do wish to make this observation, following through on the comments of my distinguished colleague from New York.

Senator, I view you as a national resource. You have got an uncanny ability to elevate discussions on very important, far reaching, and emotional issues to the highest level. And I can say personally to you that in my public career, speaking for me, personally, you have been an inspiration, and I think you are to a great many, many others in this body and across this country. And I just want to thank you from the bottom of my heart.

The CHAIRMAN. Thank you, Mr. Boehlert.

Mr. Ford?

Mr. FORD. Thank you very much, Mr. Chairman, for allowing me the opportunity to comment on this issue that we as a nation must address today.

But before I make a brief comment—I have no questions, Mr. Chairman—I would like to join my colleagues in thanking our very distinguished former Senator, Mr. Javits, for his appearance today and testifying before the full committee.

Mr. Chairman, I would just like to put several questions before the panel and the audience today and really not expect the panel to respond. But do we as legislators have the authority to determine who should live and who should die? Do we as a nation have the right to take away life, life from persons who have undergone unknown amount of pain and suffering? And do we have the right to move medical resources from one person to another simply because one case seems more terminal than the other?

And with all due respect to this distinguished panel, these decisions have to be made with the underlying belief of saving life and not ending them. And I certainly have all the respect in the world for this committee chairman and this hearing today, but I think that we, as a group of legislators and the Congress itself, should take into consideration what is being said before this committee today and other information we are privy to. And, hopefully, we can take this information and bring about some needed changes in this area, but at least still let these questions be at the top of the agenda.

With that, thank you very much, Mr. Chairman.

The CHAIRMAN. Thank you, Mr. Ford. You can be sure that that is the subject matter that will be definitely discussed and debated in this committee. When legislation is presented, it will be debated, discussed, and rediscussed in the various committees through which it will travel. It will finally get to the House and we hope it will get to the Senate. It will also be debated in discussion there. And I believe that the proper decision will be made at the time final passage of any legislation that addresses itself to this particular problem.

I thank you for your comments.

The Chair now recognizes Ms. Meyers.

Ms. MEYERS. No questions, Mr. Chairman.

The CHAIRMAN. Ms. Bentley?

Ms. BENTLEY. I have a comment, Mr. Chairman. I just want to say that I know some excellent points have been made here today. And this is a very important topic, "Dying With Dignity: Difficult Times, Difficult Choice."

I have a very—I had a personal decision to make a number of years ago when my mother—after she had suffered a stroke and been an invalid about 4 months, and then went into pneumonia. And they wanted to give her additional life-saving—the IV's and all that. And although she couldn't talk, she screamed "no, no, no." And I knew from other discussions I had with her that she just did not want to be kept alive in this manner. It was a very difficult choice for me to say let her die with dignity.

At the same time, I do want to express my tremendous respect for Senator Javits. While a newspaper reporter covering Capitol Hill, I always found him very important in giving me information, correct information about what was going on. And as I have read about his continued activities of lecturing and passing on to those who are younger his font of knowledge and his experience from real life, my hat is off to you and God bless you.

Senator JAVITS. Thank you very much.

The CHAIRMAN. The Chair recognizes Mr. McCain.

Mr. MCCAIN. Thank you, Mr. Chairman.

Before I was able to serve in the Congress, I spent a number of years working over in the U.S. Senate. During that period, I had the distinct honor and privilege of working and traveling with Senator Javits. And I believe that he brought honor, dignity, and brilliance to that body as he does bring to this issue today. And I am very deeply appreciative.

I am convinced that your presence here, Senator Javits, will go a long way toward easing the pain of millions of Americans as they face, what you describe, should be greeted with dignity and beauty.

I have a question for Dr. Viner.

Dr. Viner, in your written statement you mention that home care faces two challenges. One is technology; it is being transferred. And I quote from your statement: "From the hospital to home care and, as a result, the choices concerning the use of this technology become even more complicated."

The other challenge you discuss is Medicare. It is putting increased pressures on families providing home care. The DRG engendered earlier discharges, and therefore require increasingly skilled home supervision.

Could you give us some recommendations that you believe need to be made in Medicare in order that these challenges be overcome?

Dr. **Viner**. Yes. I think that——

Mr. **McCain**. And before you answer, I also would like to commend you on your article which I have read, "Life at the Other End of the Endo-Tracheal Tube: A Physician's Personal View of Critical Illness." I believe it should be made required reading for every physician in America.

Dr. **Viner**. Thank you very much, sir.

The problem with the home care is that this is a tremendous burden, obviously, for inexperienced family members. And very often, the patients are now being forced to go home sooner and sooner. DRG, engendered early discharge, means that because of the economic pressures on us to get people out of the hospital quickly, they are going home sicker, and they are going home needing more equipment. We are not talking about life-sustaining equipment and respirators, but simply that they are very sick and need a lot of apparatus and skill to take care of them. Families are not prepared for that.

So the families are sort of caught in a bind here and so is the doctor.

I think we need to simply expand the benefits a little bit more. We spend a lot of money in this country on health care that we are learning how to conserve somewhat. But this is not the right place to serve it. This is an unbiquitous problem that is going to happen to everyone. And a little more generosity here—take it away from someone else, perhaps, but don't skimp here.

I think what happened is that we started to make decisions to decelerate care for the dying patients. That was right. Then all of a sudden this looked like a place where we could save a lot of money. And getting them home, that seemed like a good idea. So we save more money instead of being a $500 a day bed. But we have overdone it a bit, and we have got to get off of that a little bit and spend a little more money; get patients home with a little more supervision than we are able to provide now and so forth.

But we are getting there. The system is going to sort itself out. And I think there have been extremely important developments in the last several years.

The **Chair**. Thank you, Mr. McCain.

Ms. Meyers?

Ms. **Meyers**. Mr. Chairman, I do think that this is an extremely controversial subject.

When I was chairman of public health and welfare in Kansas, I realized—this was in the State senate—I realized that due to an unusual provision in our guardianship laws that if an individual has a guardian in Kansas, no one can make the decision to withdraw heroic measures to preserve life.

We drafted a law that said that if that person who had a guardian, if two doctors said that we were not really extending life but just prolonging the dying procedure; if there was a court procedure where the individual who had the guardian was represented by counsel and it was determined that this was in the best interest of that patient and was truly his desire when he was competent to make that decision, then this decision could be made by a family member—the guardian, usually—and the doctor.

However, it just turned into a terrible fight. There were those—well, the same groups that came in and opposed the living will, when we passed it in the State of Kansas, came in and opposed this vigorously. This was not my bill, but because I was chairman of the committee, I was carrying it on the floor of the Senate, I was called a murderer. And, finally, because of this kind of controversy and mailings to everybody saying that we were murderers and all that, we withdrew the bill from the floor of the Senate and took it back to committee.

I just think that before a bill like this can be passed, there has to be a great deal of public education, that we do whatever we do very very carefully because it is fraught with controversy and real anger.

Senator **Javits**. Ms. Meyers, if I may just say a word; the anguish goes with the job, and that is what we are doing today. It certainly is not easy for me. And as I said before, I am one of those facing it. I know what is right and I know it will quiet controversy rather than stir it up as we know the confrontations and anguish the families have who face these decisions, and don't know what the person concerned would have done. And so I think we are in the process right now, thanks to Chairman Roybal, of doing what you say we must do. And so long as I can, I will continue.

Ms. **Meyers**. Well, I admire you tremendously and have been a fan of yours for a very long time. It is good to be with you today.

Senator **Javits**. Thank you.

The **Chairman**. Thank you, Ms. Meyers.

We all probably notice that a little while ago we recessed for a brief 60 seconds. All that, of course, was for the benefit of television. We continued then with the hearing, and now would like—if you all would remain exactly where you are sitting now, we have two other witnesses. They are made available to us by the Close Up Foundation, a foundation that works very closely with this committee, who is very much interested in these problems.

These witnesses, one of them comes from Tempe, AZ, Mae Chertkoff; and the other one comes from Moorhead, MN. Both would like to take a few minutes to tell us of their personal experience.

Would they please take the microphone there? Mr. Dean Bowman and Mae Chertkoff.

STATEMENT OF MAE CHERTKOFF, A PARTICIPANT IN THE CLOSE UP FOUNDATION GOVERNMENT STUDIES PROGRAM FOR OLDER AMERICANS

Mrs. CHERTKOFF. Mr. Chairman and members of the committee, on behalf of myself and other participants in this week's Close Up Program for older Americans, I thank you for the opportunity to express my views on this critical issue facing this committee.

The cost of medical care is staggering, but the emotional impact is stressful and heartbreaking to all members of the family. Our brother was ill with terminal lung cancer, but the doctors continued with hospital care and treatment until the end. When I asked the doctor to stop the agonizing torture of prolonging the life of agony with no hope of life, the answer I got was, "I'm not God."

The medical bills that came in the last 45 days of prolonged life, even God would forbid. Who has the right to decide? I believe in the living will. I can decide my fate at the time of terminal illness while I am still in sound mind, like now.

Thank you.

The CHAIRMAN. Thank you. Dean Bowman?

STATEMENT OF DEAN BOWMAN, A PARTICIPANT IN THE CLOSE UP FOUNDATION GOVERNMENT STUDIES PROGRAM FOR OLDER AMERICANS

Mr. BOWMAN. Mr. Chairman and honorable members of the committee, I am pleased to have the opportunity to testify before you today, and I appreciate the opportunity you have given the Close Up Foundation to present this hearing.

In February of this year, my mother, who was 91, decided that food was an enemy and refused to eat. After 2 weeks in three different hospitals and three different doctors interspersed with a week in the skill nursing facility of a nursing home, my wife and I decided to take her to our home.

We had a special circumstance in our home to be able to provide the kind of care required. My wife is a homemaker, and since my retirement from teaching, my work and my workshop is attached to my home. We were, therefore, able to look in on my mother 24 hours a day. We were also given assistance and the support of the Hospice of the Red River Valley.

The hospice program was complete in so many ways. They not only provided all medication required, but provided a registered nurse on call 24 hours a day. My mother died peacefully 22 days after bringing her home from the last hospitalization.

There is one fortunate aspect of our experience. My mother was fully alert and in command of all of her faculties right up to the last day. Prior to leaving the hospital on her last confinement, she demanded that the nasal-gastric feeding tube be removed. This request was honored by the attending physician. We were thus relieved of the responsibility to make decisions regarding life-support systems.

We were extremely lucky. My wife and I decided that we should relieve our children of the responsibility of having to make decisions about our lives. We had our attorney draw up living wills, outlining our wishes regarding all the basic aspects of our death, from lifesupport systems or extraordinary measures to support life, to our burial.

Mr. Chairman, I would support legislation which allows an individual the option of determining the type of medical treatment he or she would receive in the event of a terminal illness, and the legal recognition of such documents that state such options.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you very much, Mr. Bowman.

I would now like to ask one last question. I know we promised you, Senator, that we would be adjourning around 11:30. And I am sure that you will stay for just a few more minutes.

And that is a question that is constantly asked of me and this committee. I am asking this question of Dr. Viner, Senator Javits, and Ms. Mishkin.

As a sort of worst case, what should happen with the elderly person who is terminally ill, incompetent, alone, poor, and without any advanced directive? Who should decide and how in that instance?

Dr. Viner, would you like to take a crack at it first? Or the Senator?

Senator JAVITS. I would think that in that case the courts would finally be the arbiter, and they could appoint a guardian on the application of a hospital or other medical institution to represent the person in question. And then an effort would be made to ascertain from that person's history what might have been that person's decision. In the absence of that, if there is no proof available, the court would have to determine whether the likelihood would have been that that person would decide that life was not worth enduring under the condition which the person faced.

In short, I think that with the advice and factual testimony of whatever was available, even if it were the doctor alone, a court would have to decide the issue if presented. And that would represent, subject to rights of appeal, finality. I do not see any other way.

Ms. Mishkin, would you have any other view on this?

Ms. MISHKIN. I agree entirely with the Senator's response. I would add only that in making a decision, the court, I hope, would look at the burdens and the benefits of what is proposed for the patient, in view of the patient's current condition; and in looking at burdens, to look not only at the immediate pain engendered and the invasiveness of the procedure under consideration, but what that would do to the dignity of the individual. For example, would this patient have to have her hands tied 24 hours a day, as they sometimes do in nursing homes, to prevent removal of a NASO-gastric tube or of intravenous feeding equipment?

The CHAIRMAN. Dr. Viner?

Dr. VINER. Well, of course, I agree with both of my colleagues here. But, hopefully, what we would like to see is that physicians, through education and, again, further societal evolution, come to the point where they are comfortable not to let some of these monstrosity circumstances develop.

Now, the two most important decisions about a respirator are, No. 1, whether to put the patient on it in the first place; and, No. 2, whether to stop it. But if you do not put the person on in the first place, when it is inappropriate, you do not get yourself into the kind of terrible problems that we sometimes have to face. So this puts a lot of responsibility on the physician when there is no family and so forth, but with society's support, we make these decisions when we have to because there really is not any other way.

So, in summary, yes; if it comes to a need for a legal decision, that would be the way, obviously. But, most often, I think it will happen just quietly without a lot of fanfare. And the more that does occur in a way that is dignified, the more comfortable everyone will be with these kind of decisions. The more excitement and emotion, and whatever, that is stirred up by a case like Karen Ann Quinlan's, then the more the country gets all stirred up.

And to a degree, though, it is a poor analogy because it sounds undignified, but we are making a mountain out of a molehill in so many cases in the sense that we act as though there is this decision. There is no decision. Mother Nature, the Good Lord, however you look at it, has created a physical circumstance where there is no alternative. We only think there may be alternatives, so we make all this commotion over things that, unfortunately, there really is no decision to make, so often.

The **Chairman**. Thank you, Doctor.

I am sure there are many more questions that members of the committee would like to ask the panel, but we will be unable to do that because of the lack of time. If there are any pressing questions, they will be submitted to you in writing, and we know that you will respond as soon as possible.

Before adjourning this hearing, I want to express my deep appreciation and my thanks to our distinguished guests, Senator Javits, Barbara Mishkin, and Dr. Viner for their remarks and the comments that they made and shared with us today.

This has been somewhat of a depressing hearing, but is a most necessary hearing that I believe has to be duplicated in every State in the Union. I think we have responsibility of going throughout the Nation and holding these hearings. This is not only good education for us, the Members of Congress, but it serves as good education, I believe, for the public in general.

We would like to thank you for the work that you have done, Senator; Dr. Viner; and I sincerely hope that we can continue to work together in finalizing something that will be of benefit and be directed to this problem.

I would like to also thank the president of the Close Up Foundation, Mr. Steven Janger. You know, he not only came himself, but he made possible a great deal of our audience. He brought with him approximately 100 senior citizens. And he also made it possible for us to be on television this morning.

My thanks, also, to each and every one of the people who are here. Your interest is of great importance to this committee. We want to be closely associated with you and work with you in anything that pertains to any particular problem with regard to the senior citizen community of the United States.

Thank you very much. And the meeting is now adjourned.

[Whereupon, at 11:40 a.m., the hearing was adjourned.]

APPENDIXES

APPENDIX 1

Dying With Dignity: Difficult Times, Difficult Choices

A REPORT

PRESENTED BY

THE CHAIRMAN

OF THE

SELECT COMMITTEE ON AGING

ACKNOWLEDGMENTS

The Chairman of the House Select Committee on Aging gratefully acknowledges the assistance of the Congressional Office of Technology Assessment in preparing this report. In particular, Robert Cook-Deegan, Robert Harootyan, and Teresa Myers deserve special recognition for their diligent and timely assistance.

The Chairman also wishes to give a special acknowledgment to Joan Densberger, a law student of Boston College Law School, who supported the Committee staff by compiling and drafting major sections of this report.

FOREWORD

Today I am releasing this report to the House Select Committee on Aging and the House of Representatives which describes the dilemma facing America's terminally ill persons and calls for federal and state action to better assist the terminally ill.

Taken together, this report and today's Committee hearing, "Dying With Dignity: Difficult Times, Difficult Choices," are a critical first step in making the Congress and the public aware of the dilemma faced by terminally ill persons and their families. However, awareness of the dilemma is not enough.

The second step, as outlined below, is to analyze the research and knowledge on the terminally ill and to explore options for dealing with the issues surrounding the terminally ill and their care. In this regard, the two upcoming analyses by the Office of Technology Assessment, prepared at the request of the Committee on Aging and other House and Senate Committees, will be two very valuable tools. A preliminary view of these two analyses is provided in Section II of this report.

With these analyses in hand, the third and most critical step will be for the federal and state governments, the medical and legal professions, and the terminally ill and their families to join together in developing those policies which will give the terminally ill more control over medical treatment decisions.

SECTION I. ISSUES SURROUNDING AMERICA'S TERMINALLY ILL AND THEIR MEDICAL TREATMENT.

BACKGROUND ON MEDICAL TREATMENT FOR THE TERMINALLY ILL.

Death is not a subject limited to the elderly. However, elderly persons in our society are in a uniquely vulnerable position because of factors such as advanced age, constrained financial resources and physical incapacity, to mention but a few. These factors, alone or in combination, can severely impair elderly persons' abilities to manage and care for themselves even when they desire and are physically able to do so. Also, many elderly persons experience a period of prolonged chronic illness before dying, unlike an acute medical crisis or trauma situation more common in younger patient populations.

Under these circumstances, terminally ill persons should maintain control over their own lives to the greatest extent possible. This includes the freedom to make their own medical treatment decisions. Yet, we want to know that the decisions they make are truly their own, and not the product of external forces. These forces might include financial pressure either on their families or their physicians and hospitals.

The control over medical treatment decisions remains a controversial issue. Many people are most concerned about the terminally ill person's lack of a right to have medical treatment. Many other people are most concerned about the terminally ill person's right to refuse medical treatment. Given this lack of agreement, these decisions are and should remain very personal decisions. Clearly, the terminally ill need to be protected -- they need both the right to have medical treatment and the right to refuse medical treatment. *

CONFLICTING PRESSURES. In our efforts to help terminally ill persons maintain decision-making control, we must keep in mind that improvements in medical technology have given us a much greater ability to sustain life than in the past. However, this same medical technology has created very difficult choices for dying persons, their families, their physicians and society as a whole. Tragically, the dying person is the one who is being trapped in the middle — trapped in a "Catch-22" situation.

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* Under current law, people do have the right to refuse medical treatment. However, current law does not guarantee that people have the right to have medical treatment.

On the one side are the physicians with an inherent desire to sustain life. Physicians face a dilemma as they fight to keep the dying person alive while also trying to respect a dying patient's decision to refuse medical treatment. On the other side are the national policy-makers who continue to cite the high cost of caring for the dying. Some policy-makers imply that the dying have a duty to die and make way for the living.

ETHICAL CONSIDERATIONS. Under the stressful circumstances of terminal illness, a shift in decision-making power from terminally ill persons to other decision-makers tends to occur. The decision-making freedom of terminally ill persons may be subtly subsumed by others in carrying out what surrogate decision-makers perceive as their role. In some instances, this shift in decision-making occurs outright due to a court pronouncement of mental incompetency and appointment of legal guardians for the terminally ill.

The consequences of such infringements on decision-making power are drastic. Terminally ill persons may no longer have control over the most personal experience they have faced in their lives -- their own death. To the extent possible, society may want to honor the desires of terminally ill persons who want or do not want a protracted existence on artificial life-support systems. However, we must also protect the terminally ill from a coerced, involuntary decision whether it is to have or to refuse medical treatment.

COMPETENCY CONSIDERATIONS. The right to consent to or refuse treatment is a legal and ethical right of all mentally competent patients. This basic right continues to exist even when the patient subsequently becomes mentally incompetent. However, there is a legal distinction between the competent and incompetent patient insofar as their rights with respect to medical treatment. If a patient has been determined incompetent, someone else must make treatment decisions on behalf of the patient.

Because of this legal distinction, the mental competency of terminally ill persons to make decisions about their medical care is a central issue in medical decision-making. Determinations of incompetence deprive terminally persons of their freedom to exercise their right to consent to or refuse medical treatment. For the elderly patient who, for example, has been placed in a hospital or nursing home, is heavily medicated and is frightened by unfamiliar impersonal surroundings, the issue of competence is glaring.

Because of the potentially devastating consequences that determinations of incompetence have on the liberty of terminally ill persons, there is a need for a consistent and uniform approach in competency determinations. One legal standard receiving growing support is that of whether patients, including terminally ill persons, understand and appreciate the nature and consequences of their decisions regarding medical care. There is still much controversy, however, surrounding the following questions:

1) Who is questioning the patient's competency and why?
2) In what forum should competency determinations take place -- the hospital or the court?
3) Who should perform the competency determination?
4) What should be the consequence of a determination of incompetency?

SURROGATE DECISION-MAKING CONSIDERATIONS. If terminally ill persons are determined to be mentally incompetent to make treatment decisions, the crucial questions become:

1) How should surrogate decision-makers be designated?
2) Who should be the surrogate decisionmakers (e.g., family member, friend, attorney)?
3) What decisions may they make (i.e., what forms of medical treatment can the surrogate consent to or refuse on behalf of the patient)?

Terminally ill persons who have no one to act on their behalf in making medical treatment decisions present a special problem. One response by the States has been to provide for public guardianships appointed by a court.

Public guardianships have received some criticism due to the potential conflict of interest when public agencies have been appointed as guardians of wards, but are simultaneously providing services to the wards under restrictive cost constraints. For purposes of accountability, if public agencies are appointed as public guardians, the appointments should be carefully and narrowly circumscribed to the power to act only in the specific situations in which the wards are incapable of acting on their own.

ADVANCED DIRECTIVE CONSIDERATIONS. More and more attention is focusing on increasing the terminally ill person's control over their final medical treatment decisions. There is a growing push to get the public to think ahead and make some type of advanced directive. These advanced directives may be a "living will" (more appropriately termed a "natural death declaration"), a durable power of attorney or some other form of advanced directive.

The various legal devices that exist, such as the durable power of attorney and the "living will", may serve to enhance the ability of the terminally ill to have their desires carried out in the event that they are hospitalized and become mentally incompetent to make their own treatment decisions. However, since some of these mechanisms have not been tested in the courts, their application to the context of medical treatment decision-making remains questionable.

States are wrestling with various approaches to enable people to make an advanced directive. As of 1985, 35 States and the District of Columbia have enacted legislation variously termed "natural death" acts or "living will" statutes. While progress is being made by the States, there is still much to be done. As one example, the lack of uniformity and reciprocity among states with similar "advanced directives" statutes leaves in doubt the enforceability and effectiveness of an advanced directive executed in a State different from that in which terminally ill persons are hospitalized.

While executing an advanced directive is certainly to be encouraged, there is some question as to how many people will actually execute an advanced directive. Even today many people do not plan ahead and die without any type of ordinary will. In the case of persons who have always been incapacitated, there is no opportunity to make an advanced directive. In the case of the poor, the cost of executing an advanced directive is one more expense they probably cannot afford.

OTA STUDIES ON DEMENTIA AND LIFE-SUSTAINING TECHNOLOGIES.

In the course of the House Select Committee on Aging's examination of the plight of America's critically and terminally ill persons, we saw the need for an indepth assessment. The Committee, along with several other House and Senate Committees, requested that the Office of Technology Assessment (OTA) conduct two major studies. The first study is on dementia. The second is on life sustaining technologies. A preliminary view on these two studies is provided in Section II of this report.

The first OTA study is entitled "Disorders Causing Dementia." This will cover a range of issues from research on the causes of dementia to the legal, financing, social and ethical implications for the victims, their families, and society as a whole. Since certain forms of dementia, most notably Alzheimer's, are debilitating and terminal, this study will play an important role in examining the issues surrounding dying with dignity.

OTA is also engaged in a second study which is entitled "Life-Sustaining Technologies and the Elderly." This second study focuses on developments in life-sustaining technologies. The study also examines the legal, financing, social and ethical implications of these technologies for the elderly and the non-elderly. As medical science continues to advance its ability to sustain life, new questions will arise as to how to use these technologies, how to pay for them, what their impact is on the quality of life, and what are the rights of the terminally ill to refuse or require their use.

The Committee looks forward to learning from these two OTA studies. However, we also recognize that they will not be available for another year. In the interim period, we must continue our efforts to better assist the terminally ill.

CALL FOR ACTION ON BEHALF OF THE TERMINALLY ILL.

As described above, America's terminally ill are trapped in a tragic "Catch-22." While some policymakers pressure the terminally ill to make way for the living, physicians and other health care providers fight to keep the terminally ill alive. All parties need to accept that the terminally ill should have both the right to have and the right to refuse medical treatment. The terminally ill should be free to exercise both these rights without undue pressure.

Though we have much to learn about how best to relieve the pressures, enough is known so that we can better help the terminally ill. Based on an initial review of the problem and of the available solutions, I am recommending the following actions:

> **Societal pressure to contain health care costs should not be applied to the terminally ill.** They already face incredibly difficult decisions with respect to refusing or requiring medical treatment. The victims, in this case the terminally ill, should not have to carry the extra burden of society's desire to contain health care costs.
>
> **Catastrophic out-of-pocket health cost burdens for the terminally ill should be limited so that they do not create undue financial pressure on the terminally ill or bankrupt the family.** Currently, the out-of-pocket cost burden on the terminally ill and their families can be astronomical and can result in decisions to refuse medical treatment that are not in the best interests of the terminally ill person.

All States should have available legal mechanisms to enable people to make advanced directives with respect to having or refusing medical treatment. In addition to enacting the basic legislation, the States need to address the issues of the lack of uniformity and reciprocity currently existing across States and affordability and accessibility for the poor and near poor.

In determining the competency of patients, including terminally ill persons, to consent to or refuse medical treatment, their rights should be carefully protected. Much hinges on the determination of a terminally ill person's competency or incompetency. Since decision-making power, especially in the absence of an advanced directive, for a terminally ill person may be lost quickly and the consequence may be irrevocable, it is critical that competency determinations be carried out in a manner which serves the best interests of the terminally ill person.

For those terminally ill persons who are not competent to make medical treatment decisons, the courts should provide continued oversight of the designated surrogate decision-maker. In making decisions on behalf of a terminally ill person, many competing financial, ethical and societal interests may try to influence treatment decisions. As a result, the courts need to closely monitor the actions of court appointed surrogate decision-makers.

Physicians, nurses and hospitals should be sensitive not only to terminally ill persons' request to have life-sustaining medical intervention but also to their request to refuse medical treatment. No one wants health care providers to reduce their commitment to care for and sustain life in their patients. However, there is a need to balance that commitment with the commitment to provide the medical treatment that is best for the patient, as defined by the terminally ill person or their designee.

A "bill of rights" for patients, including terminally ill persons, should be affirmed legislatively; a nationwide public education program should be developed by federal and state governments to educate the public as to what are their rights with respect to medical decision-making. Though many rights of terminally ill persons may be clearly understood by lawyers and physicians, this is far from the case for the terminally ill and their families. There is a great need to make the public more aware of what are the rights of terminally ill persons and what are the options for exercising those rights.

Now is the time for federal and state governments to relieve the cost-related pressures on terminally ill persons and to give them the legal vehicles which will give them adequate control over their final days. Now is the time for physicians and other health care providers to be more sensitive to and supportive of the final wishes of America's terminally ill.

SECTION II. ISSUES SURROUNDING THE IMPACT OF LIFE-SUSTAINING TECHNOLOGIES AND DEMENTIA ON MEDICAL TREATMENT FOR THE TERMINALLY ILL. *

MRS. A

Mrs. A is an 82 year-old woman who has been in a hospital intensive care unit for 4 weeks following a stroke. A ventilator is being used to maintain her breathing. Intravenous nutritional support and hydration are being provided since she cannot eat or drink while on the ventilator. Mrs. A cannot speak because of the ventilator and cannot write due to paralysis caused by the stroke. The hospital staff and her family have noticed that she is much more alert and responsive now than she was immediately following the stroke. They believe she usually understands what is said to her and that she is aware of her physical condition.

Mrs. A's doctor believes that her condition has stabilized and that she will probably need the ventilator for the rest of her life. The doctor has discussed this with Mrs. A's only daughter, and the daughter and several other relatives have talked to the hospital social worker about finding a nursing home that will take Mrs. A. Mrs. A's sister, whom she has lived with for many years, refuses to take part in the family discussions. She says that Mrs. A told her many times that she did not want to be kept alive "on machines". The sister and a nurse on the evening shift say that they asked Mrs. A if she wanted the ventilator removed even though it meant she would die. She nodded yes. Because Mrs. A has no written document to support her wishes, the hospital administration will not allow the discontinuance of the ventilator or the intravenous nutritional support.

Mrs. A, however, cannot remain in the intensive care unit because the bed is needed for a more critically ill patient. She can be temporarily transferred to a regular medical unit, but the cost of her treatment has already exceeded what Medicare will pay the hospital for treatment of her condition, and the hospital administration is urging the doctor to make plans for discharge. The hospital social worker has contacted several nursing homes but has been unable to locate one nursing home that is willing to take a ventilator-dependent patient.

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* This section was prepared by the Congressional Office of Technology Assessment at the request of the Chairman of the House Select Committee on Aging.

DYING WITH DIGNITY: DIFFICULT TIMES, DIFFICULT CHOICES

Each day in the United States, growing numbers of elderly patients, their families, and health care providers are confronted with dilemmas concerning life and death decisions. At the request of the House Select Committee on Aging and the Senate Special Committee on Aging, the Office of Technology Assessment (OTA) is undertaking a study of "Life-Sustaining Technologies and the Elderly." * The requests for the assessment reflect growing public concern about increasingly complex situations and decision-making dilemmas exemplified by the case of Mrs. A and her family. The exact wishes of the patient are difficult to discern since no written advance directive or other type of legal instrument is available. Yet even with such a document, precise descriptions of the specific circumstances and conditions are required to be certain that a patient's desires to not receive aggressive life-support treatments are clearly understood. Given any doubt about a patient's wishes, health care decision-makers are most likely to choose aggressive treatment. At the same time, the ability to predict the outcome of such treatment is more difficult in critically ill elderly patients, who are likely to have multiple conditions that make recovery more questionable.

IMPLICATIONS OF IMPROVEMENTS IN LIFE-SUSTAINING TECHNOLOGIES. These dilemmas are expected to grow in number and complexity. Recent technological advances in the treatment of chronic diseases and acute illnesses, combined with greater access to such care, make it possible to keep alive growing numbers of persons who would not have survived in decades past. These advances, however, are accompanied by complex legal, ethical, and financial issues concerning the definition of death, patient's rights, surrogate decision-making, quality of life of the critically ill, appropriate use of life-sustaining technologies, and the influence of economic considerations on the provision of expensive and extensive health care treatments. Indeed, some studies indicate that almost 30 percent of Medicare outlays are made for care of older Americans within their last year of life. Other research, however, has shown that about one-half of all elderly Medicare beneficiaries with high-cost reimbursements survive and are discharged from the hospital. As these life-sustaining technologies become more available and increasingly feasible for use at home, questions of financial burden and the ability of individuals and society to pay for long-term health care arise.

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* The full report on "Life-Sustaining Technologies and the Elderly" will be completed in May, 1986 and published, in Summer 1986. For additional information, contact Robert A. Harootyan, Project Director (202/226-2090).

The OTA assessment examines these technological advances and their implications for the health care of older Americans. The requesting Committees of Congress expressed concern about protecting patients' rights in decision-making regarding the use of life-sustaining technologies and the extent to which aggressive intervention should be given. At the same time, the committees expressed concern about the Federal Government's role in ensuring equal access to life-sustaining technologies in the face of growing economic pressures to reduce the public costs of health care under the Medicare and Medicaid programs. On the one hand, a fundamental concern is the need to ensure that quality of life and quality of care for the elderly are not jeopardized by federal cost-containment efforts. On the other hand, congressional concerns include the need to preserve the autonomy of elderly patients and to assure their rights to choose when and to what extent life-sustaining technologies should be used. Above all else, the committees want to be sure that federal health care policies and reimbursement systems do not discriminate against elderly patients through policies that use age-based criteria to limit access to or reimbursement for health care services. Currently, 37 percent of all costs for health care of the elderly are paid out-of-pocket. Any increase in such direct costs to the elderly could influence the willingness of some to seek assistance or to desire continued aggressive intervention.

ISSUES RELATED TO THE MAJOR LIFE-SUSTAINING TECHNOLOGIES. The OTA assessment focuses on five technologies and procedures that are most relevant to the concerns expressed by the requesting Committees. Each technology reflects different aspects of the issues concerning appropriate use of life-sustaining technologies in the elderly. Renal dialysis is a required treatment for persons suffering from chronic renal (kidney) failure. These patients would die without periodic (usually every other day) dialysis treatments that are provided in hospitals, outpatient clinics, or — for some patients — at home. Dialysis is fully reimbursed by the Medicare program, which has witnessed a dramatic increase over the last decade in the number of patients receiving such care. Studies indicate that elderly patients derive considerable benefit from the treatments, significantly improving both the number and quality of years added to their lives. Some indications exist, however, that difficult decisions are made on occasion to withdraw or withhold dialysis for some types of elderly patients. The OTA assessment will attempt to discern the factors that lead to such decisions.

Another technology is prolonged mechanical ventilation, a procedure required for patients who are unable to breath independently. Ventilator-dependent patients may require continuous support, or assistance for only part of a day, depending upon the illness. In the case of Mrs. A, continuous ventilation was required because the stroke greatly diminished her ability to breath. The mobility of most ventilator-dependent patients is greatly limited, although new technologies now permit some patients to use wheelchairs along with portable ventilator units. A high degree of supportive care is required for ventilator patients, whose respiration must be monitored and airways continually checked and cleaned.

An additional life-support technology for Mrs. A is nutritional support through intravenous delivery of liquid nutrients. Mrs. A's stroke and consequent ventilation mean she cannot swallow foods or liquids. Her only source of sustenance is by intravenous feeding. Although this technology is portable and can be used in non-hospital settings, most nursing homes avoid admitting such patients. Nutritional support therapy requires expertise and added staff time to administer and monitor, thereby increasing personnel and other costs. In addition, very few nursing homes have the staff or the willingness to care for ventilator-dependent patients. As noted in the case of Mrs. A, few places exist outside the hospital where she can receive the level of care required.

The fourth technology being investigated by OTA is resuscitation. More than the previously mentioned forms of life-support, resuscitation involves specific decisions about treatment and how aggressive such treatment should be. Decisions to resuscitate are often guided by the severity of the illnesses the elderly patient has, as well as a clear understanding of the patient's wishes regarding resuscitation. The diminished "physiological reserve" of many critically and terminally ill elderly patients creates additional dilemmas in deciding whether or not to resuscitate. A successful resuscitation in such patients can also result in broken ribs, punctured lungs, or other complicating problems. These dilemmas confront health care providers on a daily basis.

The fifth technology being studied is the use of antibiotics in the elderly, especially those who are critically or terminally ill. Such individuals are particularly susceptible to infection, yet antibiotic therapy is often successful. Pneumonia was in earlier periods called "the old man's friend" because of the quiet death it brought. Today, many forms of pneumonia that were once life-threatening to the elderly can be effectively treated with aggressive antibiotic therapy. Decisions to use antibiotics to treat infections are, however, often made in light of the other conditions from which an elderly patient suffers. Again, patients, families, and health care providers are increasingly faced with life and death decisions that must weigh the degree of pain and suffering from competing illnesses that confront the elderly patient.

CONCLUSION. The OTA assessment of "Life-Sustaining Technologies and the Elderly" is reviewing these technologies and providing information on the legal, ethical, and training issues that have accompanied the availability of these increasingly sophisticated interventions. The assessment investigates the influence that the patient's age, mental status, physical condition, attitudes, and concerns about quality of life have on the decision-making process. It also reviews the influence that cost-containment efforts might have on access of the elderly to health care in general and to life-sustaining technologies in particular. Finally, the OTA assessment projects what the "next generation" of life-sustaining technologies may be and the implications they will have for an increasingly aged population in the United States.

MR. A.

> Mr. A is a 70-year old man who has developed pneumonia while living in a nursing home. The physicians, nursing home administrators, nurses, and aides are now considering whether to transfer him to a local hospital for treatment. His wife died several years ago. His daughter, who visits him once a month, is not sure whether he should be treated. His son, who resides in an adjacent state, does not want him treated.
>
> Mr. A has been in the nursing home for two years because he suffers from Alzheimer's disease. He lived with, and was cared for, by his daughter in a town 20 miles away until he began wandering out of the house and getting lost at night. Mr. A's nursing home care was initially paid for out of his savings, until his assets were depleted after nine months. He was then admitted into the Medicaid program in his state, which now pays for his care.

This fictional case illustrates many of the dilemmas that arise in the care of patients suffering from dementing disorders. What is death with dignity for a patient like Mr. A? Who should decide whether to transfer Mr. A to the hospital? Should he receive antibiotic therapy? Should his diminished ability to think, comprehend, and communicate clearly be considered in the decision to treat him? Are there programmatic or financial barriers that influence care decisions?

More than 750,000 patients like Mr. A, suffering from disorders causing dementia, currently reside in nursing homes in the United States. Issues surrounding such patients are difficult and complex to resolve, but are receiving increased public attention. The legal, medical, social, and financial aspects of public policy relating to such patients are addressed in the ongoing OTA assessment of "Disorders Causing Dementia." *

LEGAL ISSUES. Who should make the decision about whether to treat Mr. A? The courts and caregivers must attempt to determine what the patient would have wanted in this situation. This determination, however, is fraught with ambiguities, conflicts of interest, and legal uncertainties. If, for example, the son or daughter had been declared the legal guardian or conservator, then this would give an indication of who might be consulted first. However, the court appointment of a conservator or guardian may not reflect Mr. A's preference. In addition, it is not clear that guardianship carries with it the undisputed right to make critical medical decisions on behalf of the patient.

If Mr. A had an advance directive, such as a "living will" or durable power of attorney, that might also yield clues as to his desires. However, advance directives have varying degrees of legal standing, and may or may not cover a patient's particular situation (e.g., whether to treat with antibiotics).

MEDICAL CONSIDERATIONS. In addition to the legal ambiguities, there is also tremendous medical uncertainty. A physician cannot predict whether Mr. A will live for a month, a year, or a decade if he is treated. He can predict that his Alzheimer's disease will progress but cannot determine the rapidity of deterioration with any accuracy. Furthermore, no health professional can determine Mr. A's assessment of his own quality of life.

Uncertainty also surrounds the antibiotic treatment itself. Optimal medical treatment would include admission to the hospital, multiple laboratory tests, evaluation of other medical problems, and treatment with one or more antibiotics that might or might not cure the pneumonia. Each step in this process has its own sources of error and risk, which add up to medical uncertainty about whether to treat the patient.

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* The OTA project will be completed in July, 1986. The staff contact at OTA is Robert Cook-Deegan, M.D. (202/226-2034). The project addresses many issues in addition to those noted in this background document, including federal policies on biomedical research and provision of long-term care for patients with dementia.

If Mr. A leaves the nursing home for the hospital, he may lose his bed at the nursing home. Difficulty in placing him back in a nursing home from the hospital may make the hospital reluctant to admit him. At least three factors would make Mr. A a relatively unattractive candidate for admission back into a nursing home. First, he is covered by Medicaid which pays less than most private pay patients. Second, he suffers from dementia, and many nursing home personnel consider the care of such patients difficult. Third, the mental symptoms due to his Alzheimer's disease could lead to his classification as a 'mental' patient. If more than half the residents of a nursing home are 'mental patients,' then the home risks loss of certification for Medicaid payment. While recent changes in Medicaid regulations specifically state that Alzheimer disease and related disorders are not 'mental' disorders, misclassification of patients based on their symptoms can still occur, and implementation of the new regulations is incomplete.

FINANCIAL FACTORS. Mr. A's nursing home care is now paid for by both the State and Federal Governments through the Medicaid program. Federal outlays for nursing homes were $12 billion in 1983, of which an estimated 50 percent were for patients with dementing conditions. States paid a roughly equal amount.

If Mr. A were admitted to the hospital, his medical care there would likely be borne by a combination of Medicaid and Medicare. Under Medicare, the hospital would receive a fixed payment to treat Mr. A's pneumonia (the amount would be determined by the diagnosis of pneumonia). This means that the hospital gets the same amount regardless of the number of tests administered and whether or not he is effectively treated. Under Medicaid, how the hospital was paid would depend on his state of residence. In some States, the hospital would be paid for individual procedures and treatments; in others it would receive prospective payment, either according to diagnosis (like that under Medicare) or through fixed monthly or annual payments for each patient. If Mr. A were covered under Medicare, the Medicaid payments would pick up most costs not covered under Medicare.

The rapid increase in costs of health care have lead to a growing focus on cost containment. Both the Federal and State Governments are searching for ways to limit escalating budget outlays for health care. Will such concern for budget austerity lead to constraints on whether patients like Mr. A are treated? Such constraints could be due to limited payments for certain diagnoses or procedures, or could follow from financial difficulties and consequent changes in hospital policies over the long run.

For patients like Mr. A, there are several possible problems with prospective payment systems like that now in the Medicare program. First, a hospital may have disincentives to admitting him if he is deemed likely to develop complications or require extensive evaluation of secondary medical problems. The disinclination to admit him derives from the fixed nature of the payment for his primary diagnosis of pneumonia, which would not pay for such complications or extra tests except by resort to a special mechanism that requires documentation and extra paperwork. Second, Mr. A may not be admitted if he is deemed likely to be difficult to discharge, either to a nursing home or elsewhere.

PERSONAL AND SOCIAL VALUES. All decisions about medical care are made in the context of predominant social and personal values. These values can be expressed by the patient (in Mr. A's case through knowing his past views), his family, physicians, nurses, aides, social workers, and administrators.

Social values vary from 'treatment at all costs for all patients' to concern that public funds not be spent to unnecessarily prolong the dying process for those who are hopelessly ill and are perceived to have a low quality of life. These values are incorporated into Government health care programs. The problems in admission to hospitals and nursing homes faced by patients with dementia listed above, for example, are due to decisions made and included in public health care programs. The institutional practices of nursing homes, hospitals, and other health care institutions also reflect social values

Each individual brings his or her own biases and professional perspective to decisions about treatment. Physicians may have one opinion, family members another, and aides involved in daily care yet another.

CONCLUSION. Decisions about medical treatment, acute health care, and long-term care are complex and involve many social values, distinct and often conflicting personal views of those involved, and are made in an environment increasingly focused on costs. Such decisions are difficult for those who are aware of their own plight, and even more complicated for those affected by a dementing disorder.

APPENDIX 2

UNIFORM LAWS ANNOTATED

Volume 9

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UNIFORM LAW COMMISSIONERS' MODEL HEALTH-CARE CONSENT ACT

Historical Note

The Model Health—Care Consent Act was approved by the National Conference of Commissioners on Uniform State Laws in 1982. The complete text of the act, the prefatory note and comments are set forth in this supplement.

Commissioner's Prefatory Note

"Every human being of adult years and sound mind has a right to determine what shall be done with his own body, and a surgeon who performs an operation without his patient's consent commits an assault for which he is liable in damages." Scholendorff v. Society of New York Hospitals, 211 N.Y. 125, 105 N.E. 92 at 93 (1914).

That often quoted statement of Judge Cardozo both states the premises underlying this Act and suggests by omission the subject matter of the Act. What if the human being is not of adult years and of sound mind or is otherwise unable to consent? Assuming consent is nonetheless required, who can give an effective consent? These questions plague hospital administrators, physicians and surgeons daily. They are also of grave importance to patients, their families and friends. Some certainty in this area of the law is needed for all the participants in the health care system, consumers as well as providers.

Scope of the Act

This Act is procedural in nature and is purposefully narrow in scope. Its primary aim is to provide authorization to consent to health care. It does not address the substantive issues of consent; for instance, what constitutes informed consent, whether informed consent is required or under what circumstances one has a right to refuse treatment.[1]

Many of the substantive aspects of consent involve conflicting social and ethical values. The law's response to many consent issues is halting and uncertain. It is reflective of the ambivalence in society. For instance, the right to refuse treatment raises questions about which there is no clear consensus in American law. The many ethical and moral dilemmas presented in those cases dealing with the right to refuse psychotropic drugs or the right to refuse necessary medical care suggest that further experimentation is in order to propose a model solution for these questions would stifle creativity and is neither practicable nor desirable.

The "who" questions of consent (who is authorized to consent for himself or for another) do not, in the routine cases, present serious, unresolved moral issues. Yet, at best, the law on these questions is far from clear and has been described as "haphazard".[2]

This Act is drafted to provide assistance in the cases that occur daily and routinely in medical practice. It is not designed to provide answers for the extraordinary cases, such as terminal illness, organ donation, and the treatment of mental illness. These extraordinary cases present separate and discrete problems involving not only issues of competency but of the authority of a substitute decision-maker as well. To force a single solution to these many problems would be

[1] While numerous states adopted informed-consent legislation within the last decade, others declined to do so. There is no reason to believe that those states with informed-consent legislation are dissatisfied with their efforts nor is there reason to believe that uniform legislation on this subject would be enacted by those states that decided not to adopt informed-consent legislation in the 1970s. Basically, informed-consent legislation is an idea whose time has come—and gone. In addition and by way of illustration of its narrow scope, this Act is not concerned with: whether, how and under what circumstances liability will be imposed on a health care provider for failing to obtain consent; whether and to what extent consent requirements are relaxed in emergencies; whether consent must be express or implied; the evidentiary problems that arise in proving that consent was in fact obtained; or how much and what kind of information must be provided to the patient to satisfy the standards of informed consent.

[2] Kindregan, The Courts as a Forum for Life and Death Decisions: Reflections on Procedures for Substitute Consent, 11 Suffolk L.Rev. 919, 924 (1977). For a particularly enlightening discussion of many of the problems of "substitute consent" see A. Meisel, The "Exceptions" to the Informed Consent Doctrine: Striking a Balance Between Competing Values in Medical Decision-making, 1979 Wis.L. Rev. 413, 473–488 (hereinafter Meisel).

at best a procrustean fit. To provide a statutory solution to the problem of the administration of antipsychotic medication to a noninstitutionalized incompetent person which is consistent with the due process clause would be completely unworkable if the problem to be solved is how to render treatment to a child with a broken arm while its parents are on an extended trip.

While this Act does not, indeed cannot, solve all the myriad and complex issues of consent, it can serve a very useful function. In an effort to replace the murkiness of custom with the clarity of legislation and to provide guidance for those involved daily with the problem of how medical decisions are to be made for an individual who cannot do so for himself, this Act embraces five general concepts.

First, the Act designates the individuals who may consent to health care for themselves. (Section 2.) Section 2 restates the common law that adults may consent for themselves unless incapable of consenting. At common law, minors were not permitted to make health-care related decisions and the state entrusted that decision-making power to parents. However, over the years there have developed several well-defined exceptions to a minor's disability. Section 2 incorporates those more widely recognized exceptions. In addition to the general exceptions to the status of minority which permit minors to consent to all forms of health care, many states have carved out more limited exceptions that authorize minors to consent to particular forms of health care without parental consent, for instance, treatment for drug or alcohol abuse. Section 2 preserves existing state law on these matters.

Second, the Act provides a triggering mechanism to determine when an individual is incapable of consenting. (Section 3.) This decision is made by the health-care provider and the standard for determining that one is incapable of consenting is whether the individual is capable of making a decision regarding the proposed health care. It is important to note that the effect of a determination of incapacity is not to bypass consent but to shift the health care decision-making to a third party.

Third, the Act provides a scheme for determination of a proxy decision-maker to act for one incapable of consenting. (Section 4) At common law, parents were entrusted with making health care decisions for their children. The state's power to care for an incompetent adult was traditionally exercised through guardianship. That much is clear in existing law. However, unless the person in need of health care is an infant or has been accorded protection through a formal adjudication of incompetency, the common law affords no clearly established authorization for one family member to act for another. Courts and treatise writers have indicated that authorization from a spouse or other close family member is permissible.[3] While that accords with custom, actual adjudicated authority to that effect is sparse. Section 4 provides both an authorization and system of priorities for proxy decision-makers.

Fourth, the Act permits family members authorized to consent for another by Section 4 to delegate their authority to make health-care decisions. (Section 5) The authorization is intended to permit relatives to delegate their decisional power while they are separated from other family members. For instance, while children are away at summer camp the power of a parent to delegate decisional authority to a camp director would be extremely useful.

Fifth, the Act authorizes an individual to appoint another to serve as a health-care representative and to make health-care decisions on his behalf. (Section 6) A concern for personal autonomy underlies this provision. Section 6 is designed to provide an alternative to the system of third-party consent outlined in Section 4. Section 6 permits an individual to make his own designation if he so chooses. While the provision is perhaps novel to the field of health care, the power to make such a designation exists in jurisdictions that have statutes similar to the Uniform Durable Power of Attorney Act.

One authorized to make health-care decisions for another is in every important sense of that word a fiduciary. A proxy decision-maker must use good faith and act in the best interest of the individual for whom decisions are made. Those authorized to act under Section 4 are empowered to act either because of a legally imposed relationship (in the case of a guardian) or because of a family relationship. A health-care representative authorized under Section 6 is empowered because a patient has designated him to make treatment decisions; autonomy is the basis for the appointment.

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[3] See Meisel, supra note 3.

The best interest standard governs both a Section 4 proxy and a Section 6 health-care representative. In the case of a Section 4 proxy, best interest incorporates an objective general standard, whereas the Section 6 health-care representative must also act in accordance with the purposes of the individual as stated in the appointment. Best interest is an evolving standard governed by state law. In the case of Section 4 proxy, best interest requires that the decision maker act reasonably. In most cases the Section 4 decision-maker will be a family member. His power does not arise from the patient having placed him in a position of trust but from his relationship to the patient. His power thus turns on the community's perception of what authority a relative ought to have. That is generally defined in terms of an objective best interest test. However, the Section 6 health-care representative acts because he has been designated to serve by the patient. Autonomy is the basis for that appointment and the health-care representative's obligation can be determined from the creator of the power, i.e., from the specific instructions in the document appointing him. When the patient has expressed his desire, that is the strongest evidence of his best interest.

There are important limitations on the substitute decision-maker's power contained in the Act. One of the most important limitations concerns the treatment of mental illness. The Act does not displace existing law on the consent related questions of mental-health treatment. One important issue that has been the subject of recent litigation concerns the right to refuse psychotropic drugs in the treatment of psychosis. Some litigated cases require prior *judicial* approval for the administration of these drugs to nonconsenting, noninstitutionalized, incompetent persons. See In the Matter of Guardianship of Roe III, — Mass. —, 421 N.E.2d 40 (1981). Many difficult questions remain unanswered; for instance whether absent an emergency, a state can forcibly medicate an involuntarily institutionalized person without a prior judicial determination of incapacity. See Mills v. Rogers, — U.S. —, 102 S.Ct. 2442 (1982). This is one of those areas in which there is no clear consensus and Section 11 of the Act preserves that ongoing debate. Section 11 does not authorize any individual to consent to mental-health treatment unless in compliance with state law.

UNIFORM LAW COMMISSIONERS' MODEL HEALTH-CARE CONSENT ACT

Sec.

1. Definitions.
2. Individuals Who May Consent to Health Care.
3. Individuals Incapable of Consenting.
4. Individuals Who May Consent to Health Care for Others.
5. Delegation of Power to Consent to Health Care for Another.
6. Health-care Representative: Appointment; Qualification; Powers; Revocation and Responsibility.
7. Court-Ordered Health Care or Court-Ordered Appointment of a Representative.
8. Disqualification of Authorized Individuals.
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10. Availability of Medical Information.
11. Effect on Existing State Law.
12. Severability.
13. Uniformity of Application and Construction.
14. Short Title.
15. Repeal.
16. Time of Taking Effect.

Law Review Commentaries

Uniform and Model Acts in 1980 (part 1). Maurice H. Merrill. 52 Okl. B.J. 677 (1981).

§ 1. Definitions

As used in this [Act]:

(1) "Adult" means an individual [18] or more years of age.

(2) "Health care" means any care, treatment, service, or procedure to maintain, diagnose, or treat an individual's physical or mental condition.

(3) "Health-care provider" means a person who is licensed, certified or otherwise authorized by the law of this State to administer health care in the ordinary course of business or practice of a profession.

(4) "Minor" means an individual who is not an adult.

(5) "Person" means an individual, corporation, business trust, estate, trust, partnership, association, government, governmental subdivision or agency, or any other legal entity.

Commissioners' Comment

The age of 18 is bracketed in the definition of an adult (subsection (1)) so that states with a different age for achieving adult status may insert whatever age is appropriate.

Health care (subsection (2)) includes any care, treatment, service or procedure to diagnose or treat a physical or mental condition. The term is broader in scope than medical care and includes care and treatment which is lawful to practice under state law, for instance, nursing care.

Since the definition of health care is broader in scope than medical care, there is a need to limit the coverage of the Act so that the rendition of routine care by family members would not be within its coverage. One limitation on the scope of the Act is found in the definition of a health-care provider in subsection 3. That definition excludes those who are not licensed, certified or otherwise authorized to render health care. Hence, the rendition of simple care by a family member to one who is ill at home would not be covered by this Act while that same treatment would be covered if provided in a hospital.

Library References

Assault and Battery ⇐2.
Physicians and Surgeons ⇐15(8).

C.J.S. Assault and Battery §§ 2 to 4, 6 to 8.
C.J.S. Physicians and Surgeons § 48.

§ 2. Individuals Who May Consent to Health Care

Unless incapable of consenting under Section 3, an individual may consent to health care for himself if he is:

(1) an adult; or

(2) a minor and

(i) is emancipated,

(ii) has attained the age of [14] years and, regardless of the source of his income, is living apart from his parents or from an individual in loco parentis and is managing his own affairs,

(iii) is or has been married,

(iv) is in the military service of the United States, or

(v) is authorized to consent to the health care by any other law of this State.

Commissioners' Comment

Section 2 describes those individuals who may consent to health care for themselves.[1] All adults, unless disqualified by Section 3, may consent to health care. These two provisions basically restate the common law with regard to consent by adults. At common law minors were not presumed to be competent to consent to health care. However, there are certain status exceptions, both statutory and common law, which render a minor capable of consenting. Section 2(2) is a compilation of the more widely recognized exceptions to the traditional requirement of consent by a parent or guardian which permit a minor, unless disqualified by Section 3, to consent to health care for himself as if he were an adult.

The exceptions are based on the assumption that a minor who has made the described decisions or taken the described actions in his life has demonstrated his capacity to make decisions concerning his health care. The emancipated minor exception is widely recognized in case law and in the statutes of more than thirty states. See Wilkins, *Children's Rights: Removing the Parental Consent Barriers to Medical Treatment of Minors*, 1975 Arizona St. L.J. 31, 59 (1975). Paragraph (2)(ii) is an explicit emancipation provision based on objective criteria which will not require a formal adjudication of emancipation. The age is bracketed, but the age of 14 is a reasonable age when coupled with the other requirements of this paragraph.

Other objective criteria which courts and state legislatures have accepted as showing a minors' maturity to make decisions affecting his health, are marriage and service with the armed forces. (See, e.g., Ind.Ann.Stat. 16-8-4-1 (Burns 1973).) Once a minor has satisfied any of these criteria he may consent to health care for himself as if he were an adult.

In addition to the status exceptions permitting consent by minors, many legislatures have created additional exceptions authorizing minors to consent to treatment for specific conditions or diseases without regard to their status. For instance, 45 states presently allow minors to obtain treatment for venereal disease without parental consent. One or more states permit minors to consent to the following forms of health care:

(1) health care necessary to diagnose or treat pregnancy;

(2) health care necessary to diagnose or treat venereal disease;

(3) health care necessary to diagnose or treat alcohol or drug dependency or abuse;

(4) psychiatric or psychological counseling;

(5) health care necessary for the performance of an abortion;

(6) health care necessary for counseling in the use of contraceptive devices; and

(7) health care necessary for the performance of any type of sterilization.

Paragraph 2(v) of this Act leaves intact those state laws which permit a minor to consent to one or more specific health-care procedures, regardless of whether the minor meets the status exceptions of paragraph 2.

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[1] While the language of Section 2 is cast in terms of an authorization to consent, that necessarily means that one authorized to consent may also refuse consent or withdraw consent to a course of health care once given.

Library References

Assault and Battery ⟸2, 11.
Physicians and Surgeons ⟸15(8).

C.J.S. Assault and Battery §§ 2 to 4, 6 to 8, 16, 17.
C.J.S. Physicians and Surgeons § 48.

§ 3. Individuals Incapable of Consenting

An individual otherwise authorized under this [Act] may consent to health care unless, in the good faith opinion of the health-care provider, the individual is incapable of making a decision regarding the proposed health care.

Commissioners' Comment

Section 3 uses the phrase incapable of consenting as opposed to incompetency. This choice is deliberate. Incompetency in American law carries the connotation of permanency and is often thought to involve an adjudicative declaration. However, a person may be *de jure* competent when in fact he is incapable of making a decision regarding his own health care. An otherwise competent adult who has been rendered unconscious in an accident is at that time *de facto* incompetent or incapable of making a decision regarding proposed health care.

Section 3 is phrased negatively as the law presumes that adults, and under certain circumstances minors as well, are capable of making decisions unless there is some determination of a contrary status. The determination called for in Section 3 is to be made by the health-care provider, and the standard is whether the individual is incapable of making a decision regarding the proposed health care. If the individual is capable of making a decision, the health-care provider must abide that decision.

Custom suggests and necessity dictates that the initial determination that one is incapable of consenting rest with the health-care provider. Section 3 in recognition of necessity legitimates that custom. Unlike the decision to invoke the emergency exception to the requirement of informed consent which has the effect of bypassing consent altogether, a decision that one is incapable of consenting merely shifts the decision regarding the rendition of health care to a third party. This is an important difference for the health-care provider's decision is *ex necessitae* a "low visibility" one. Any decision to bypass the patient by deciding that he is incapable of making a decision endangers the values of individualism and personal autonomy. What is needed in any such decision is a proper combination of deference to professional judgment and health-care values on the one hand and respect for personal autonomy and individualism on the other. Reposing the ultimate decision to proceed with medical treatment in a third party should assure that values of personal autonomy and individualism receive proper consideration.

The requirement that the individual be incapable of engaging in decision-making is consistent with the underlying notion of consent. A unique human characteristic is the power to make decisions. The language of Section 3 focuses on the ability of one to make a decision as opposed to the content of a health care decision. A decision to refuse a specific course of treatment may be based on moral or religious grounds. An individual who refuses treatment because he has consistently relied on prayer for healing in accordance with his religious tradition is capable of making his own health-care decisions. A decision to refuse treatment made under those circumstances should be honored by a health-care provider.

The uncertainties of medical practice and the decision to be made do not make precise statements of the test for determining incapacity easy. However, the context in which the decision is made and the effect of such a decision render the lack of precision less onerous.[1] The health-care provider who decides that one is incapable of consenting must then turn to another who is charged with making the ultimate treatment decision in the best interest of the patient.

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[1] See A. Meisel, The "Exceptions" to the Informed Consent Doctrine: Striking a Balance Between Competing Values in Medical Decisionmaking, 1979 Wis.L.Rev. 413, 453, 472–473.

Library References

Mental Health ⟹31.

C.J.S. Insane Persons § 90 et seq.

§ 4. Individuals Who May Consent to Health Care for Others

(a) If an individual incapable of consenting under Section 3 has not appointed a health-care representative under Section 6 or the health-care representative appointed under Section 6 is not reasonably available or declines to act, consent to health care may be given:

(1) by a guardian of his person, a representative appointed under Section 7, or a representative designated or appointed under other law of this State; or

(2) by a spouse, parent, adult child, or adult sibling, unless disqualified under Section 8, if there is no guardian or other representative described in paragraph (1) or he is not reasonably available or declines to act, or his existence is unknown to the health-care provider.

(b) Consent to health care for a minor not authorized to consent under Section 2 may be given:

(1) by a guardian of his person, a representative appointed under Section 7, or a representative designated or appointed under other law of this State;

(2) by a parent or an individual in loco parentis, if there is no guardian or other representative described in paragraph (1) or he is not reasonably available or declines to act, or his existence is unknown to the health-care provider; or

(3) by an adult sibling of the minor, if a parent or an individual in loco parentis is not reasonably available, declines to act, or his existence is unknown to the health-care provider.

(c) An individual delegated authority to consent under Section 5 has the same authority and responsibility as the individual delegating the authority.

(d) A person authorized to consent for another under this section shall act in good faith and in the best interest of the individual incapable of consenting.

Commissioners' Comment

Section 4 authorizes designated persons to exercise health-care decision-making powers for individuals who cannot consent for themselves and who have not appointed a health-care representative to act on their behalf as authorized in Section 6. If a health care representative has been appointed and is willing to act, that preempts the operation of this section.

Subsection (a) is concerned with adults and minors authorized to consent under Section 2. It sets forth an order of priority among substitute decision-makers. The first priority is given to individuals appointed by a court, a guardian or an individual appointed under Section 7. The second priority class is the family. Within this class, the spouse, parents, adult children and adult siblings are ranked equally. Any member of the class is authorized to act. Any decision establishing priority among family members would be largely arbitrary. The objective is to have someone who has a close personal relationship with the patient and who will consider his best interest acting for him. If one of those authorized to act disagrees with the decision of another who has been designated a proxy decision maker, that person can seek formal judicial appointment to act for the one incapable of consenting. However, an objector would be required to show that the other authorized decision-maker was not acting in the patient's best interest. (See Section 7.)

Subsection (b) authorizes substitute decision-makers for minors who are not authorized to consent under Section 2. The first priority is given to court-appointed officials. If the parents are alive, it is unlikely that there would be a court-appointed guardian and the parents would have first priority. If there is no court-appointed official and if the parents are unavailable, any adult brother or sister of the minor is authorized to make health-care decisions.

Family members authorized to consent for one incapable of consenting under this section may delegate their decisional authority to another. The person to whom authority is delegated under Section 5 has the same priority to act for the patient as the delegating individual.

One authorized by this section to act for another must act in good faith and in the best interest of the individual incapable of consenting.

Library References

Husband and Wife 🔑1.
Mental Health 🔑236.
Parent and Child 🔑1.

C.J.S. Husband and Wife § 1 et seq.
C.J.S. Insane Persons § 85.
C.J.S. Parent and Child §§ 3 to 4, 10.

§ 5. Delegation of Power to Consent to Health Care for Another

(a) An individual authorized to consent to health care for another under Section 4(a)(2), 4(b)(2) or 4(b)(3) who for a period of time will not be reasonably available to exercise the authority may delegate the authority to consent during that period to another not disqualified under Section 8. The delegation must be in writing and signed and may specify conditions on the authority delegated. Unless the writing expressly provides otherwise, the delegate may not delegate the authority to another.

(b) The delegant may revoke the delegation at any time by notifying orally or in writing the delegate or the health-care provider.

Commissioners' Comment

Section 5 permits a limited delegation of authority to consent for another. Family members authorized to consent for another under Section 4 may delegate their decisional authority. This provision should be helpful in situations in which parents want to delegate health-care decision-making to a temporary custodian of their children, for instance when parents plan to be away or when a child is at camp. This section follows closely Section 5-104 of the Uniform Probate Code.

Library References

Mental Health ⟹179, 236. C.J.S. Insane Persons §§ 49, 86.

§ 6. Health-care Representative: Appointment; Qualification; Powers; Revocation and Responsibility

(a) An individual who may consent to health care under Section 2 may appoint another as a health-care representative to act for the appointor in matters affecting his health care.

(b) A health-care representative appointed under this section must be an individual who may consent to health care under Section 2.

(c) An appointment and any amendment thereto must be in writing, signed by the appointer and a witness other than the health-care representative and accepted in writing by the health-care representative.

(d) The appointor may specify in the writing terms and conditions considered appropriate, including an authorization to the health-care representative to delegate the authority to consent to another.

(e) The authority granted becomes effective according to the terms of the writing.

(f) The writing may provide that the authority does not commence until, or terminates when, the appointor becomes incapable of consenting. Unless expressly provided otherwise, the authority granted in the writing is not affected if the appointor becomes incapable of consenting.

(g) Unless the writing provides otherwise, a health-care representative appointed under this section who is reasonably available and willing to act has priority to act for the appointor in all matters of health care.

(h) In making all decisions regarding the appointor's health care, a health-care representative appointed under this section shall act (i) in the best interest of the appointer consistent with the purposes expressed in the appointment and (ii) in good faith.

(i) A health-care representative who resigns or is unwilling to comply with the written appointment may exercise no further power under the appointment and shall so inform (i) the appointor, (ii) the appointor's legal representative, if one is known, and (iii) the health-care provider, if the health-care representative knows there is one.

(j) An individual who is capable of consenting to health care may revoke: (i) the appointment at any time by notifying the health-care representative orally or in writing, or (ii) the authority granted to the health-care representative by notifying the health-care provider orally or in writing.

Commissioners' Comment

Section 6 is designed to extend the concept of patient autonomy by permitting a person to transfer his health care decision-making power to another. Many individuals who are competent to make health care decisions nevertheless want to delegate this decisional authority to a relative or friend. In addition, in the event they are rendered incapable of consenting, many people want the assurance that some other individual whom they trust will make health-care decisions on their behalf.

It is generally thought that if one cannot or does not exercise his own decisional authority in health-care matters this authority should be placed in the hands of the state (i.e., a court), a health-care provider or the next of kin. Any of these choices may be seen as a restriction on autonomous choice. Leaving this authority in the hands of a court when there are other alternatives available is particularly vexing because it allows the state a measure of control over individuals to which it has no obvious moral right and for which it has no special expertise. Section 6 provides an alternative. The decision to allow the transfer of authority rests on the principle of the basic human need of self determination and individual autonomy. The patient himself can designate the person who is to make those health-care decisions. Section 6 does not proscribe the nature of the decision-making relationship between the appointing individual and the person appointed. The appointing individual has the opportunity to engage in moral discourse with his agent, and to specify in the document the terms and the conditions of the appointment.

Subsection (b) provides that a health-care representative must act in the best interest of the appointor consistent with the purposes expressed in the appointment and in good faith. Cases often purport to draw a distinction between a best interest and substituted judgment standard. (Compare In re Guardianship of Pescinski, 67 Wis.2d 4, 226 N.W.2d 180 (1975) (best interest) with In re Quinlan, 70 N.J. 10, 355 A.2d 647 (1976) (substituted judgment)). Yet the two terms reflect not so much a difference in concept as a difference in emphasis. The standard of best interest is generally thought to incorporate a concept of objective reasonableness with reference to the interests of society and others while the substituted judgment standard focuses on the interest of the particular patient. That the patient may define what is in his best interest and that such a declaration should be accepted by surrogate decision-maker is well recognized in many adjudicated cases. (See In re Quinlan, 70 N.J. 10, 355 A.2d 647 (1976); Superintendent of Belchertown State School v. Saikewicz, 370 N.E.2d 417 (Mass.1977) and Eichner v. Dillon, 426 N.Y.S.2d 517 (1981)).

Personal autonomy is the basis for the concept of the health-care representative in Section 6. Where a person appointing a health-care representative has given particular instructions, those instructions should define the best interest of a patient. If no specific directions are given, the more general best interest standard applies.

If the health-care representative cannot in good conscience follow the directions provided by his appointor he must resign or seek relief from that mandate by a court. The health-care representative would be an interested individual entitled to petition a court under Section 7. In the event the health-care representative does not act, consent must be obtained from one of those individuals authorized in Section 4 to act for the patient or from a court under Section 7.

Section 6 is consistent with the Uniform Durable Power of Attorney Act. The appointment made under this section would be given effect without this Act in a jurisdiction which has enacted the Durable Power of Attorney Act. By incorporating this section into the Act, the power of appointment will be brought to the attention of persons who may not be aware of the Durable Power Act.

Because the power of appointment is unique, the Conference concluded it was desirable to set forth a suggested form instrument to be used for the appointment of a health-care representative.

Appointment of a Health-Care Representative

I, the undersigned, voluntarily appoint ______________________________
whose telephone number and address are: ____________________________
____

as my health-care representative who is authorized to act for me in all matters of health care, except as otherwise specified below.

This appointment is subject to the following special provisions:
____
____
____
____

This appointment (becomes effective) (remains effective) (terminates) if I later become disabled or incapable of consenting to my health care. I (do) (do not) authorize my health-care representative hereby appointed to delegate decision-making power to another.

Dated this ____________ day of ________, 19___.

____
(signed)

____
(address)

I declare that at the request of the above-named individual making the appointment, I witnessed the signing of this document.

____
(signed)

____
(address)

Acceptance by Health-Care Representative

I, the undersigned health-care representative, understand that acceptance of this appointment means that I have a duty to act in good faith and in the best interest of the individual appointing me. I further understand that I have a duty to follow any special instructions in the appointment. In the event I cannot do so, I will exercise no further power under the appointment and will inform (i) the individual appointing me, if that individual is capable of consenting, (ii) his/her legal representative, if known to me, and (iii) his/her health-care provider if known to me.

Dated this ____________ day of ________, 19___.

____
(signed)

____
(address)

Library References

Mental Health 🔑118, 174.

C.J.S. Insane Persons §§ 37, 40, 47.

§ 7. Court-Ordered Health Care or Court-Ordered Appointment of a Representative

(a) A health-care provider or any interested individual may petition the [________] court to (i) make a health-care decision or order health care for an individual incapable of consenting or (ii) appoint a representative to act for that individual.

[(b) Reasonable notice of the time and place of hearing a petition under this section must be given to the individual incapable of consenting and to individuals in the classes described in Section 4 who are reasonably available.

(c) The court may modify or dispense with notice and hearing if it finds that delay will have a serious, adverse effect upon the health of the individual.]

(d) The court may order health care, appoint a representative to make a health-care decision for the individual incapable of consenting to health care with such limitations on the authority of the representative as it considers appropriate, or order any other appropriate relief in the best interest of that individual, if it finds:

(1) a health-care decision is required for the individual;

(2) the individual is incapable of consenting to health care; and

(3) there is no individual authorized to consent or an individual authorized to consent to health care is not reasonably available, declines to act, or is not acting in the best interest of the individual in need of health care.

Commissioners' Comment

Section 7 is designed to operate in two basic situations. The first is that in which an individual is in need of health care and incapable of consenting and there is no one to act on his behalf. It is not infrequent that a person admitted to a hospital has no known relatives or friends. The second is that in which one authorized to act is not acting in the best interest of the individual who is incapable of consenting. If the parents of a minor refuse medical treatment because of the parents' religious convictions courts have not hesitated to take the decision-making authority from the parent when the child's life is endangered.[1]

The removal of a parent's power to consent is generally taken pursuant to state child neglect statutes. However, in some instances courts simply assume the decision-making authority under the *parens patriae* doctrine. Section 7 provides for the same kind of relief that is provided in the child neglect statutes. Section 7 provides a certain and expeditious means for removing one authorized to consent who is not acting in the best interest of a patient. The Act does not attempt to define best interest. There is a developing body of law on that question; however, its contours are not yet clear. (See M. Wald, *State Intervention on Behalf of "Neglected" Children: A Search for Realistic Standards*, 27 Stan.L.Rev. 985, 1031–1033 (1975).

Any health-care provider or any individual is given standing to petition for the appointment of a competent representative to consent to the rendition of health care. A court acting pursuant to this section is authorized to order health care or to appoint a competent representative who is authorized to make health-care decisions. This section does not displace any other state procedures designed to accomplish the same result. Because most states have existing mechanisms to address these questions, the purely procedural portions of Section 7, subsections (b) through (d) are bracketed. They may be deleted from the Act without destroying its integrity.

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[1] On occasion, courts have ordered treatment over the parents' objection even though the proposed treatment was not necessary to save the child's life but posed substantial risks and was not certain to cure the condition. (See In re Sampson, 317 N.Y.S.2d 641 (1970) affirmed 29 N.Y.2d 900, 328 N.Y.S.2d 686 (1972).) In Sampson, the minor suffered from a massive overgrowth of facial tissue causing a severe deformity on the right side of his face and neck. The need for treatment was shown by testimony that he did not attend school and suffered a severe learning disability relating to the deformity. The court concluded that the disfigurement so limited the child's development that it had to assume responsibility and order the surgery, even though the procedure entailed obvious risks. (For a contrary result, see In re Seiferth, 309 N.Y. 80, 127 N.E.2d 820 (1955).)

Library References

Mental Health ⟹218, 236.

C.J.S. Insane Persons §§ 79, 85.

§ 8. Disqualification of Authorized Individuals

(a) An individual who may consent to health care for himself under Section 2 may disqualify others from consenting to health care for him.

(b) The disqualification must be in writing, signed by the individual, and designate those disqualified.

(c) A health-care provider who knows of a written disqualification may not accept consent to health care from a disqualified individual.

(d) An individual who knows he has been disqualified to consent to health care for another may not act for the other under this [Act].

Commissioners' Comment

A full recognition of individual autonomy requires not only that one be authorized to appoint his health-care representative but that he also be authorized to say whom he does not want to act for him. Section 8 permits this disqualification. A patient may not want to go through the formality of appointing a Section 6 health-care representative but may well wish to exclude certain persons from acting on his behalf.

One who is disqualified under Section 8 has no authority to act. However, unless that disqualification is known to a health-care provider, he may nevertheless rely on an authorization from one who is disqualified. (See Section 9.)

Library References

Mental Health 🔑116. C.J.S. Insane Persons §§ 42, 43.

§ 9. Limitations of Liability

(a) A health-care provider acting or declining to act in reliance on the consent or refusal of consent of an individual who he believes in good faith is authorized by this [Act] or other law of this State to consent to health care is not subject to criminal prosecution, civil liability, or professional disciplinary action on the ground that the individual who consented or refused to consent lacked authority or capacity.

(b) A health-care provider who believes in good faith an individual is incapable of consenting under Section 3 is not subject to criminal prosecution, civil liability, or professional disciplinary action for failing to follow that individual's direction.

(c) A person who in good faith believes he is authorized to consent or refuse to consent to health care for another under this [Act] or other law of this State is not subject to criminal prosecution or civil liability on the ground he lacked authority to consent.

Commissioners' Comment

Under Section 9, the health-care provider is permitted to rely on the consent of an individual whom he believes in good faith is authorized to consent to health care. In meeting this standard under the Act, a health-care provider could not close his eyes to the truth, of course, but to prescribe an affirmative requirement of detailed investigation would make reliance impossible.

Similarly, a health-care provider who makes a determination that one is incapable of consenting and thus calls in a third-party decision-maker is not subject to liability for discharging his obligation in good faith.

An individual acting for another is in every sense of the word a fiduciary and has those obligations which a fiduciary owes his ward. The immunity provided in this section does not protect a substitute decision-maker from negligence or other breach of duty but only from acting without authority if he in good faith believes that he is authorized to give consent.

Library References

Mental Health 🔑179. C.J.S. Insane Persons § 49.

§ 10. Availability of Medical Information

An individual authorized to consent to health care for another under this [Act] has the same right as does the individual for whom he is acting to receive information relevant to the contemplated health care and to consent to the disclosure of medical records to a contemplated health-care provider. [Disclosure of information regarding contemplated health care to an individual authorized to consent for another is not a waiver of an evidentiary privilege.]

Commissioners' Comment

An individual authorized to consent for another stands in the shoes of the patient when making health-care decisions. The individual authorized to consent is entitled to receive information relevant to the proposed health care whether or not that is allowable under any other provision of state law. This section guarantees that right but makes no attempt to define the scope of disclosure required.[1]

In many cases, proper diagnosis and treatment require that medical information must be passed from one doctor or hospital to another. Because of the confidential or privileged nature of much of this information, the patient's consent is necessary before the information can be disclosed. (61 Am.Jur. 2d Physicians & Surgeons § 101 (1972) and 20 A.L.R.3d 1109 (1968).) To the extent that the patient has a right which can be waived, an individual acting on his behalf has the same right of waiver. The Act does not determine whether confidential information or a privilege exists in the first instance.

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[1] For a detailed bibliography of informed consent see A. Meisel, The Expansion of Liability for Medical Accidents: From Negligence to Strict Liability By Way of Informed Consent, 56 Neb.L.Rev. 51, 75 n. 64 (1977) and A. Meisel, The Exceptions to the Informed Consent Doctrine: Striking A Balance Between Competing Values in Medical Decisionmaking, 1979 Wisc.L.Rev. 413 n. 3.

Library References

Physicians and Surgeons 🔑15(8).
Witnesses 🔑208(1).

C.J.S. Physicians and Surgeons § 48.
C.J.S. Witnesses §§ 293, 312.

§ 11. Effect on Existing State Law

(a) This [Act] does not affect the law of this State concerning an individual's authorization to make a health-care decision for himself or another to withdraw or withhold medical care necessary to preserve or sustain life.

(b) This [Act] does not affect the requirements of any other law of this State concerning consent to observation, diagnosis, treatment, or hospitalization for a mental illness.

(c) This [Act] does not authorize an individual to consent to any health care prohibited by the law of this State.

(d) This [Act] does not affect any requirement of notice to others of proposed health care under any other law of this State.

(e) This [Act] does not affect the law of this State concerning (i) the standard of care of a health-care provider required in the administration of health care, (ii) when consent is required for health care, (iii) informed consent for health care, or (iv) consent to health care in an emergency.

(f) This [Act] does not prevent an individual capable of consenting to health care for himself or another under this [Act], including those authorized under Sections 4, 5 and 6, from consenting to health care administered in good faith pursuant to religious tenets of the individual requiring health care.

Commissioners' Comment

Section 11 contains important limitations. It is written to make clear that this Act does not intrude into areas of the law where its operation would be inappropriate.

The law with respect to the withdrawal of life support systems in the case of the terminally ill is changing rapidly. At least 10 states have Natural Death Acts and there have been several court decisions concerning the issue of termination of treatment. Nothing in this Act changes existing law in that regard. All proxy decisionmakers are charged with acting in the best interest of the patient who is incapable of consenting. If a patient had appointed a health-care representative and had made known his wish that life support systems be withdrawn in the event of terminal illness, many courts would consider that evidence conclusive of the patient's best interest. However, this Act does not provide an answer to the question of what is in the patient's best interest in such a circumstance.

Subsection (b) provides that the Act will not override the operation of mental health codes. All states require that commitment proceedings be surrounded with stringent procedural safeguards which must be adhered to before an individual can be involuntarily committed. Subsection (b) makes it clear that this Act does not allow any individual authorized to consent for another to bypass those commitment statutes under the guise of a voluntary commitment. In addition, subsection (b) prohibits this Act from being used to authorize forcible drug medication unless in conformity with other proper procedural requirements.

Subsection (c) is written to make it clear that this Act does not authorize one to consent to medical procedures which are prohibited by law.

The Supreme Court has held in Bellotti v. Baird, 443 U.S. 622 (1979) that minors are entitled to consent to an abortion without parental consent. That holding is recognized in Section 2 which permits minors to consent to health care which is otherwise authorized by law. However, the Supreme Court held in the case of H. L. v. Matheson, 450 U.S. 398, 101 S.Ct. 1164 (1981) that a state requirement of notice to parents does not violate the constitutional rights of a minor. Subsection (d) is written to ensure that state statutes, such as the Utah statute under review in *Matheson*, are not affected by this Act.

This Act is narrow in scope. It is not concerned with the standard of care required of health-care providers. It is not concerned with whether, how and under what circumstances consent to health care is required. Nor is it an informed consent statute. As outlined in the Prefatory Note, this statute is basically a procedural one and matters of state substantive law are unchanged.

Section 2 of this Act limits health-care providers to those who are licensed, certified or otherwise authorized to provide health care. Practitioners of religious healing, for instance, Christian Science Practitioners are not licensed, certified or authorized by the state but practice as a matter of the free exercise of religion. Yet spiritual healing is a well recognized form of health care and there is no intention to make this religious activity illegal by the operation of this Act. There is no intention to prevent an individual capable of consenting to health care from consenting for another or himself to spiritual healing which is health care administered in good faith pursuant to religious tenets of the individual requiring health care as a matter of free exercise of religion. Certainly those practitioners of religious healing should not be required to seek state authorization to practice their faith. Hence, subsection (f) is an express savings clause to permit one to consent to spiritual healing as health care.

Library References

Assault and Battery 🔑2, 11.
Physicians and Surgeons 🔑15(8).

C.J.S. Assault and Battery §§ 2 to 4, 6 to 8, 16, 17.
C.J.S. Physicians and Surgeons § 48.

§ 12. Severability

If any provisions of this [Act] or the application hereof to any person or circumstance is held invalid, the invalidity does not affect other provisions or applications of the [Act] which can be given effect without the invalid provision or application, and to this end the provisions of this [Act] are severable.

Library References

Statutes 🔑64(1).

C.J.S. Statutes § 92 et seq.

§ 13. Uniformity of Application and Construction

This [Act] shall be applied and construed to effectuate its general purpose to make uniform the law with respect to the subject of this [Act] among states enacting it.

Library References

C.J.S. [illegible]ies § 388.

Statutes ⟹236.

§ 14. Short Title

This [Act] may be cited as the Uniform Law Commissioners' Model Health-Care Consent Act.

§ 15. Repeal

The following acts and parts of acts are repealed:

(1)

(2)

(3)

§ 16. Time of Taking Effect

This [Act] shall take effect ____________.

†

AS APPROVED
~~FOR APPROVAL~~

UNIFORM RIGHTS OF THE TERMINALLY ILL ACT

NATIONAL CONFERENCE OF COMMISSIONERS
ON UNIFORM STATE LAWS

MEETING IN ITS NINETY-FOURTH YEAR
MINNEAPOLIS, MINNESOTA

AUGUST 2-9, 1985

UNIFORM RIGHTS OF THE TERMINALLY ILL ACT

UNIFORM RIGHTS OF THE TERMINALLY ILL ACT

SECTION 1. DEFINITIONS.

In this [Act]:

(1) "Attending physician" means the physician who has primary responsibility for the treatment and care of the patient.

(2) "Declaration" means a writing executed in accordance with the requirements of Section 2(a).

(3) "Health-care provider" means a person who is licensed, certified, or otherwise authorized by the law of this State to administer health care in the ordinary course of business or practice of a profession.

(4) "Life-sustaining treatment" means any medical procedure or intervention that, when administered to a qualified patient, will serve only to prolong the dying process.

(5) "Person" means an individual, corporation, business trust, estate, trust, partnership, association, government, governmental subdivision or agency, or any other legal entity.

(6) "Physician" means an individual [licensed to practice medicine in this State].

(7) "Qualified patient" means a patient [18] years of age or older who has executed a declaration and who has been determined by the attending physician to be in a terminal condition.

(8) "State" means a state, territory, possession, or commonwealth of the United States and the District of Columbia.

(9) "Terminal condition" means an incurable or irreversible condition that, without the administration of life-sustaining treatment, will, in the opinion of the attending physician, result in death within a relatively short time.

SECTION 2. DECLARATION RELATING TO USE OF LIFE-SUSTAINING TREATMENT.

(a) Any individual of sound mind and [18] years of age or older may at any time execute a declaration governing the withholding or withdrawal of life-sustaining treatment. The declaration must be signed by the declarant, or another at the declarant's direction, and witnessed by 2 individuals.

(b) A declaration may, but need not, be in the following form:

DECLARATION

> If I should have an incurable or irreversible condition that will cause my death within a relatively short time, and if I am no longer able to make decisions regarding my medical treatment, I direct my attending physician, pursuant to the [__________ Uniform Rights of the Terminally Act], to withhold or withdraw treatment that only prolongs the dying process and is not necessary to my comfort or to alleviate pain.

Signed this ________ day of ________, ____.

Signature ______________________

Address ______________________

The declarant voluntarily signed this writing in my presence.

Witness ______________________________
Address ______________________________

Witness ______________________________
Address ______________________________

(c) A physician or other health-care provider who is provided a copy of the declaration shall make it a part of the declarant's medical record and, if unwilling to comply with its provisions, promptly so advise the declarant.

SECTION 3. REVOCATION OF DECLARATION.

(a) A declaration may be revoked at any time and in any manner by the declarant without regard to mental or physical condition. A revocation is effective upon communication to the attending physician or other health-care provider by the declarant or by another who witnessed the revocation.

(b) The attending physician or other health-care provider shall make the revocation a part of the declarant's medical record.

SECTION 4. RECORDING DETERMINATION OF TERMINAL CONDITION AND DECLARATION.

Upon determining that the declarant is in a terminal condition, the attending physician who knows of a declaration shall record the determination and the terms of the declaration in the declarant's medical record.

SECTION 5. TREATMENT OF QUALIFIED PATIENTS.

(a) A qualified patient has the right to make decisions regarding life-sustaining treatment as long as the patient is able to do so.

(b) A declaration becomes operative when (1) the declaration is communicated to the attending physician and (2) the declarant is determined by the attending physician to be in a terminal condition and no longer able to make decisions regarding administration of life-sustaining treatment. When the declaration becomes operative, the attending physician and other health-care providers shall act in accordance with its provisions or comply with the transfer provisions of Section 6.

(c) This [Act] does not affect the responsibility of the attending physician or other health-care provider to provide treatment, including nutrition and hydration, for comfort care or alleviation of pain.

(d) Unless the declaration otherwise provides, the declaration of a qualified patient known to the attending physician to be pregnant shall be given no force or effect as long as it is probable that the fetus could develop to the point of live birth with continued application of life-sustaining treatment.

SECTION 6. TRANSFER OF PATIENTS.

An attending physician or other health-care provider who is unwilling to comply with this [Act] shall as promptly as practicable take all reasonable steps to transfer care of the declarant to another physician or health-care provider.

SECTION 7. IMMUNITIES.

(a) In the absence of knowledge of the revocation of a declaration, a person is not subject to civil or criminal liability or discipline for unprofessional conduct for carrying out the declaration pursuant to the requirements of this [Act].

(b) A physician or other health-care provider, whose actions under this [Act] are in accord with reasonable medical standards, is not subject to criminal or civil liability or discipline for unprofessional conduct.

SECTION 8. PENALTIES.

(a) A physician or other health-care provider who willfully fails to transfer in accordance with Section 6 is guilty of [a class _________ misdemeanor].

(b) A physician who willfully fails to record the determination of terminal condition in accordance with Section 4 is guilty of [a class _________ misdemeanor].

(c) An individual who willfully conceals, cancels, defaces, or obliterates the declaration of another without the declarant's consent or who falsifies or forges a revocation of the declaration of another is guilty of [a class _________ misdemeanor].

(d) An individual who falsifies or forges the declaration of another, or willfully conceals or withholds personal knowledge of a revocation as provided in Section 3, is guilty of [a class _________ misdemeanor].

(e) Any person who requires or prohibits the execution of a declaration as a condition for being insured for, or receiving, health-care services shall be guilty of [a class _________ misdemeanor].

(f) Any person who coerces or fraudulently induces another to execute a declaration under this [Act] shall be guilty of [a class _________ misdemeanor].

(g) The sanctions provided in this section do not displace any sanction applicable under other law.

SECTION 9. GENERAL PROVISIONS.

(a) Death resulting from the withholding or withdrawal of life-sustaining treatment pursuant to a declaration and in accordance with this [Act] does not constitute, for any purpose, a suicide or homicide.

(b) The making of a declaration pursuant to Section 2 does not affect in any manner the sale, procurement, or issuance of any policy of life insurance or annuity, nor does it affect, impair, or modify the terms of an existing policy of life insurance or annuity. A policy of life insurance or annuity is not legally impaired or invalidated in any manner by the withholding or withdrawal of life-sustaining treatment from an insured qualified patient, notwithstanding any term to the contrary.

(c) A person may not prohibit or require the execution of a declaration as a condition for being insured for, or receiving, health-care services.

(d) This [Act] creates no presumption concerning the intention of an individual who has revoked or has not executed a declaration with respect to the use, withholding, or withdrawal of life-sustaining treatment in the event of a terminal condition.

(e) This [Act] does not affect the right of a patient to make decisions regarding use of life-sustaining treatment so long as the patient is able to do so, or impair or supersede any right or responsibility that any person has to effect the withholding or withdrawal of medical care.

(f) Nothing in this [Act] shall require any physician or other health-care provider to take any action contrary to reasonable medical standards.

(g) This [Act] does not condone, authorize, or approve mercy-killing or euthanasia.

SECTION 10. PRESUMPTION OF VALIDITY OF DECLARATION.

A physician or other health-care provider may presume, in the absence of knowledge to the contrary, that a declaration complies with this [Act] and is valid.

SECTION 11. RECOGNITION OF DECLARATION EXECUTED IN ANOTHER STATE.

A declaration executed in another state in compliance with the law of that state or this state is validly executed for purposes of this [Act].

SECTION 12. EFFECT OF PRIOR DECLARATIONS.

An instrument executed before the effective date of this [Act] that substantially complies with Section 2(a) shall be given effect pursuant to the provisions of this [Act].

SECTION 13. SEVERABILITY.

If any provision of this [Act] or its application to any person or circumstance is held invalid, the invalidity does not affect other provisions or applications of this [Act] which can be given effect without the invalid provision or application, and to this end the provisions of this [Act] are severable.

SECTION 14. TIME OF TAKING EFFECT.

This [Act] takes effect on ____________________.

SECTION 15. UNIFORMITY OF CONSTRUCTION AND APPLICATION.

This [Act] shall be applied and construed to effectuate its general purpose to make uniform the law with respect to the subject of this [Act] among states enacting it.

SECTION 16. SHORT TITLE.

This [Act] may be cited as the Uniform Rights of the Terminally Ill Act.

SECTION 17. REPEAL.

The following acts and parts of acts are repealed:

(1)

(2)

(3)

APPENDIX 3

Medicine and Humanity

Prog. crit. Care Med., vol. 2, pp. 3–13 (Karger, Basel 1985)

Life at the Other End of the Endotracheal Tube: A Physician's Personal View of Critical Illness

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Introduction

Having considered the technical and scientific aspects of acute lung injury and mechanical ventilation, it is time to pause and remember that there is a living, thinking, feeling, and frightened human being on the other end of that machine. While it is incompatible with our self images as empathetic care providers, having had a serious personal experience with illness, I can assure you that none of us *really* know what we doctors ask our patients to endure, and what a devastating physical and emotional experience it is to be critically ill. The facts of my particular case really do not matter, other than to provide the perspective from which I speak, and to make all of this a little less sterile and academic. Besides the specific medical details of his case, each patient brings his own personality and psychosocial background to his illness, all of which affect that individual's ability to cope with the stress of his ordeal. The physician must be ever mindful of all of this in considering his patient on the other end of the tube, whom illness has reduced to an eye-watering, lip-quivering mass of protoplasm.

Case Presentation

I was a 34-year-old hematologist working with critically ill and dying patients every day, when, on May 2, 1972, at the behest of my then pregnant wife, I went for the first complete physical examination of my adult life. While in every respect I anticipated a purely routine venture, the examining physician communicated an unspoken message of alarm as he paused in examining my liver. Having established that there was marked enlargement of the right lobe, a liver scan was performed the next day. After literally grabbing the scan out of a reluctant radiologist's hand, and seeing for myself the large cold area in the right lobe, I then joined the downcast herd of patients inevitably found in X-ray department waiting rooms. I immediately identified with these unfortunates, whose doctors, like mine, were doing X-rays looking for cancer. As I proceeded to have a chest film, intravenous pyelogram and long upper GI, all in search of the presumed occult primary tumor, I sat there terror stricken, trying to deal with the mental images of my cachectic, end-stage, cancer patients, and my speculation as to whether I would still be alive when our baby came that August. In between studies, I called home to tell my wife about the findings, and that I would be admitted to the hospital. I called my secretary to have her cancel all my patients, *forever*, and called my insurance agent, accountant, and attorney to meet me in my hospital room that afternoon. I, as most doctors, did not have my personal affairs in order, and properly attending to all of this ultimately was to provide me with significant peace of mind in the weeks to come.

The following morning I had a bone marrow examination, proctoscopy and barium enema, all of which were normal. At this point it seemed likely that the lesion was a primary hepatic tumor and a subsequent arteriogram confirmed that it was almost surely a hepatoma. It was decided that exploratory surgery should be performed, but this was delayed by the development of a deep venous phlebitis, which in combination with a low-grade fever, only served to reinforce further my certainty that I indeed had a hepatic malignancy. Finally, on May 16, surgical exploration of my liver through a thoracoabdominal approach was carried out. The lesion fortunately proved to be a huge benign hemangioma, but I really did not believe my doctors were telling me the truth concerning the pathology, even though I was shown the reports firsthand, and ultimately was visited by the chief of pathology. Only weeks later, after being put on the respirator, and realizing that my senior attending surgeon, Dr. *Jonathan Rhoads,* was too sensible to put me through all this, if indeed I had had an inoperable malignancy, did I really become secure that the pathology was truly benign.

The first five postoperative days were spent in the intensive care unit, with tubes coming out of everywhere, but this experience did not prove particularly difficult. However, soon after being transferred out of the unit, I began to have a recurrent spiking fever requiring hours on an ice blanket each day for more than two weeks. Multiple thoracenteses, bronchoscopic examinations, and various scans failed to reveal the cause, and ultimately it was presumed that there must be a subhepatic collection of pus. Accordingly, I was to be operated upon again.

I went to the second surgical procedure again very frightened, not because of fear of malignancy this time, but with a temperature of nearly 105°, I felt too sick to go to surgery safely. My first awareness postoperatively was the bank of lights overhead, indicating that I was back in the intensive care unit and that I was too sick to be brought back to my private room. As the scene unfolded, the large overhead clock, and the darkness outside, told me that it was 3.00 a.m., and the presence of my surgeon further alarmed me since the chairman of surgery does not come in for routine postoperative problems in the middle of the night. I then also realized that I was packed in ice cubes, and from bits and pieces of the conversation that I overheard, I concluded that I had indeed been found to have a large abdominal abscess, that I had developed Gram-negative septicemic shock and, in short, was in *bad trouble*. The subsequent days were to confirm that perception, and more.

The next night with the endotracheal tube in place, I began to vomit. I was awake and alert and wanted to pull the tube and bite block out of my mouth so I could vomit over the side of the bed. I realized that I might aspirate, and indeed, later knew that I was doing so, even though the nurse told me 'everything is under control; you can't be aspirating because of the balloon on the endotracheal tube'. Over the next couple of days I developed a combination of aspiration pneumonia and shock lung, and finally after becoming totally exhausted from the work of breathing, I wrote my wife a note, telling her that I could not last more than a few more hours unless something different could be done. At my request, she called in my close friend, the former head of the hospital's respiratory intensive care unit, who was away on vacation. Dr. *Robert Rogers*, now Chief of the Pulmonary Section of the University of Pittsburgh, responded immediately, and quickly taught me that there is a real *art* to running a respirator. I am still not really sure of all that he did, but within several hours I was breathing infinitely more comfortably and the immediate crisis had passed. There was more yet to come, however. A tracheotomy became necessary, and I subsequently learned that the complication of 'PEEP' is 'POP' as I begun a series of pneumothoraces requiring multiple chest tubes.

The final statistics summarizing my misadventure include 120 days in the hospital, 31 days on the respirator, 10 chest tubes, 13 thoracenteses, 118 arterial blood gases (without benefit of an arterial line, and which I calculated one night trying to while the hours away, required a rough average of 3.2 sticks per specimen), hundreds of hours on the ice blanket, 3 bronchoscopic examinations, and 7 months out of work. It was a year before I really felt well again with no further chest or abdominal pain or overt dyspnea. Along the way, there were many indelible lessons learned, which, until then, I had thought, in a superficial intellectualization, to be self-evident.

Perceptions from the ICU Experience

First of all, we doctors really have no concept of that which we ask our patients to endure physically and emotionally, all at a time when they are most vulnerable, physically and emotionally. Patients would benefit immeasurably if every care provider could experience the preoperative terror of thinking he has an end-stage malignancy, the nostalgia inherent in believing that he will not see his children grow up, and the preterminal mourning over the thought that he is leaving behind everyone whom he knows and loves. It is clear that if the illness is serious enough, even the most resolute patient will meet his match. While I had started out feeling strong, both physically and emotionally, by the end of the 31-day stint on the respirator, I had literally become that labile, eye-watering, lip-quivering mass of protoplasm that we physicians have all seen on the end of the endotracheal tube.

The patient lives in a very circumscribed world. Accordingly, everyone who enters his day assumes a magnified role. While the doctor is theoretically the 'leading man' in the cast of characters, he is there for only a few minutes once, or at most, several times daily. Therefore, it is the nurse with whom the patient literally lives his day, who is really the most important of all. However, the patient's world also includes various paraprofessional and support personnel, on down the hierarchical ladder to the ward clerk, the paperboy and the 'environmental engineer' who mops the floor around the bed. It is unfortunate that these people do not realize the importance of their roles in the patient's life, and are not prepared for this responsibility. A warm smile instead of an air of oblivious indifference makes all the difference to the patient on a respirator.

As stated, it is the nurse, and not the doctor, who is the single most important person in the critically ill patient's life. In turn, the single most important attribute of the nurse is *whether she cares*. I thought I could tell with great accuracy whether an individual nurse did or did not, and I quickly decided that there were basically two types, angels and bitches. However, it also became clear that there was also a third group comprised of nurses who, no doubt, had been excellent, but who had been in the intensive care unit too long. While they were fine technicians when it came to aspirating a patient and doing other procedures, the human qualities had been lost. I lay there trying hard to define just what defines a 'good nurse', and finally decided that it is a combination of warmth and sensitivity with a significant degree of professionalism which are the key ingredients. I learned that there is a remarkable degree of nonverbal communication between the respirator patient and the nurse. Her moods, attitudes, basic intelligence and ability, her personality and her personal problems all interact to affect the bottom line for the patient. I found myself concerned about who was coming on the next shift. Some inspired confidence; with others I could expect a confrontation. I was also surprised with my concern over the personal appearance of my nurses. If her uniform was dirty or sloppy, I became concerned that her care would be similar. I resented undignified behavior in the unit; loud noise and raucous laughter seemed inappropriate and incongruent to my personal situation of being half dead on that machine. Whereas I ordinarily would have smiled at some of the interchanges between a surgical resident and nurse in the middle of the night at the nurses' station, that was not in keeping with the raison d'être of their being there, which from my limited vantage point was to keep me alive.

One of the most frustrating aspects was the custom of rotating the nurses. The rationale seemed to be that no one nurse should get too involved with a given patient, although from the patient's point of view, this boiled down to having one first date after another. By the end of the shift, just when a given nurse had learned how to aspirate and position me in the least painful way possible, she was replaced by someone I had never seen before, and with whom I had to go through the same learning experience all over again. I also got a bit paranoid about why the nurses were being changed all the time. 'Didn't they like me?' 'Did I smell bad?' 'Wasn't I a good patient?'

Many of these feelings also applied to the physicians, particularly the house staff. There was a tremendous difference between how the various surgical residents cared for me. It was obvious that some either refused to get involved, or really did not know how, at a personal level. On the other hand, my senior surgeon who had performed both operations, was caring and totally in charge. I came to realize how vital it was for there to be a steady 'captain of the ship', for it was easy to see how quickly one's care could deteriorate to the level provided when a committee of subspecialists is collectively in charge.

Another basic issue also applies equally to doctors, nurses and all health care providers. It is a problem, on the other hand, with which I have some sympathy, for even now, in spite of the unique learning experience my illness provided, I find myself, nonetheless, forgetting to *listen to the patient*. There were countless examples over the many weeks in the ICU when this basic failure made life difficult and, at times, even dangerous for me. As noted, the night I aspirated what seemed to me a gallon of gastric juice, I was awake and tried to tell the nurse in charge that I was aspirating, and that it would be better if she pulled the endotracheal tube and bite block out and simply let me vomit. I was told, 'My, my, my, don't we know a lot about ourselves'. With the first pneumothorax, I tried to explain that I was short of breath, but the attitude was that I had been short of breath for a week, so what was new? Well, this was new, and different, and I knew something was wrong, although I knew not what. Finally, it was the respiratory therapist, and not a doctor, who recognized that I had a tension pneumothorax (the surgical resident refused to come over from the nursing station to listen to my chest). While on hyperalimentation, an erroneously large dose of insulin was given on one occasion, following which I had the classical symptoms and signs of an acute hypoglycemic episode. I was cold and soaking wet, and felt absolutely bizarre up there on cloud nine. When I tried to explain this to both the nurses and the surgical house staff, I was told that I could not possibly have a hypoglycemic reaction with 50% glucose running. It remained for a physician not involved with my care, who was visiting the patient in the next bed, to recognize that the pleas I was writing on the clipboard were correct, and to speed up the IV enough to raise my blood sugar. In truth though, we will never know if my diagnosis was correct, for I never was able to get anyone to draw the blood sugar which would have vindicated me. The respiratory patient in particular is dependent both on the machine, and on the care provided. Beside the basic frustration inherent in not being in control of one's destiny, it was also frightening to realize that the staff did not always respect one's observations about himself.

While, appropriately enough, great attention was given to the operation of the respirator, my blood gases, and the other parameters by which I was followed, after a time I became rather ambivalent about all of this and really was much more concerned about creature comfort. This is something hard to come by in the ICU situation. Basically, I hesitated to ask for amenities, when others around me were also very ill. I longed for one of those old-fashioned private duty nurses we so irreverently called 'biddies', whose whole purpose would be to fluff my pillow and position me comfortably. Naturally, I was told that type of nurse was not allowed in the ICU, and that such an individual would just be in the way of the more crisis-oriented, and sophisticated, unit staff. I tried to tell them that I really did not care about the machine any more, that the President would have a creature comfort nurse, that I would pay for it, etc., but it was all to no avail.

After a time, having long since lost any ability to control the situation physically, I also began to lose emotional control. At times I was frankly psychotic. Intermittently I realized this, and was both very frightened and embarrassed by it. While intellectually I knew what was happening to me, and that it would pass if I survived, nonetheless, I became quite concerned about whether I would be whole again mentally. I also worried that I would never be able to function as a doctor again. I thought about asking to see a psychiatrist, but decided that he really could not help in view of the existing physical situation. I also was a little embarrassed to acknowledge that I needed this type of help, which was an unfortunate mistake. In coherent moments I could understand the reason for specific delusional ideas, dreams and nightmares. For example, it was not surprising to find myself both insecure and concerned about the lack of privacy when I found myself on the back of a flat-bodied truck in the middle of a corn field at a state fair in Kansas. My demand to be put back in the ICU at the University Hospital where I would be safe, made obvious sense, and my annoyance at being gawked at by the surrounding spectators was understandable in view of the lack of privacy in the ICU situation. I came to know John Kennedy very well as we both sat in the bottom of PT boat 109, a concept engendered by the 'putt putt' sound made by water in the respirator tubing which is not unlike a boat motor. I was repeatedly concerned that the place was being robbed and no one was doing anything about it, perhaps reflecting the stealing away of my health without recourse. Frequently, when the bed sheet was stained with a drop of blood, I asked for a new one. The nurses had trouble understanding that during the night, the werewolves and vultures came and ate any blood spots, leaving me cold and shivering with a cover full of holes. I was appreciative of those who were wise enough to react to my mental aberrations with a sensible, straightforward attempt to reorient me, and angry later with anyone who led me on during one of my 'trips'.

Towards the end of the ICU experience, when sleep deprivation, morphine and the intensity of my physical problems were no longer interacting to produce psychotic thinking, this was replaced by fear that I just would not be able to hack it emotionally until I could escape from the unit. I began to cry at the sight of my wife entering the room, and at the mention of the family dog, let alone our children. On the last day, when there was a retraction of the promise that I could leave the unit that morning, because my blood gases were not adequate, I told my doctor that I just could not stand it there any longer, and that I absolutely had to go. If there is heaven on earth, it is the private room to which I was transferred, where it was clean and quiet, and where my very own private duty nurse could take care of my basic need for comfort, without being a slave to the respirator and its attendant demands.

I am often asked if I suffered much pain during this experience. In actuality I did not, and indeed pain, when it was an issue, seemed readily relieved by morphine. A more important and difficult challenge was being just plain *miserable*. Under this heading, I include the problem of being chronically uncomfortable, with multiple chest tubes making it impossible to move or breathe without a sharp reminder, and the raw post-tonsillectomy feeling in one's throat after a nasogastric tube has been in place for 31 straight days. Also included in the misery category are the problems of nausea, abdominal cramps, and hiccoughs, of feeling dirty, with no decent bath or shampoo for many weeks, the bad taste of an oral fungus infection, and multiple other minor indispositions. Sleep deprivation was also a very difficult contributing problem for me. For the first five days on the respirator, I essentially had no sleep and finally bargained with my doctor to close the curtain around the bed and leave me totally alone for two hours so that I could regain the strength to go on. I remember very vividly telling him that if I died, I died. Time, in general, passed at a snail's pace, and most nights seemed interminable.

The problems of communicating were serious and varied. It was very difficult to write everything laboriously on a clipboard all of those weeks on the respirator. Indeed, one of my very favorite visitors was one of the hospital research staff, who had been totally deaf since early childhood, and as a result, could read lips expertly. For him, communicating with me was no different than with anyone else. With little to divert me, I became terribly tired of thinking about myself incessantly. Finally, Dr. *Rogers* brought me a transistor radio, and I suddenly again became aware of an outside world. There were even those times when the problem of communication was dangerous. On two occasions, the janitor pulled the respirator plug out of the socket without realizing it, leaving me on a closed system with no movement of air. I am told that emergency alarms were supposed to go off, but my only memory was having to detach the respiratory tube from the tracheostomy myself in order to breathe room air.

Another question commonly asked of me concerns whether I thought about dying. This was an all-pervading and relentless issue, though my thoughts ultimately became quite ambivalent. Most of the time I was very frightened that I would, though I derived some comfort, during the long hours I spent preoccupied with this issue, from the fact that I had had the opportunity to arrange my economic affairs in a way that would enable my children to be educated and my wife to be comfortable. There were other times, however, when I was so tired of plugging on, that I wished I would just go to sleep forever. Lastly, at times there were some thoughts about committing suicide. I was frightened by such thoughts, and it took the nurses some time to understand the origin of my occasional questions concerning whether the unit windows were locked. Much of the time was spent thinking nostalgically about my family and about all the everyday things we take for granted, but which now suddenly were to be no more. I would not see the Philadelphia Eagles play again or again drive along the River Drive at cherry blossom time, or see who would win the election. Later, I realized that all this constituted a type of preterminal mourning process. One of the most distressing aspects of my preoccupation with dying was a recurrent dream which I had many times a night even after I was convalescing at home. Simply stated, I was placed on a stretcher, just as I had been for countless excursions to X-ray, the OR, Physical Therapy, etc. This trip, however, took me down into the bowels of the hospital where a door was opened into a room with five tables. On four of the tables were bodies and the fifth one, in the middle, was empty. At that point the morgue attendant indicated that I was to climb up there, and my autopsy began.

There was little opportunity to talk about all of this, and in fairness to my doctors and nurses, I gave little indication of my preoccupation with death and dying. On one Sunday morning, however, I did finally tell the assembled group at the bedside that I was very fearful of that possibility and that I had to talk about it. True to storybook fashion, each person in the retinue physically drew back in response. The distance was perhaps only a quarter inch, but it was perceptible and obvious, and my reaction was to feel somewhat sorry that I had laid such a difficult situation on them. I realized that nowhere in our training at the time, had anyone taught us how to deal with such a statement from a patient. My senior surgeon, Dr. *Rhoads*, however, responded straightforwardly and appropriately to my pleas, communicating openly that the physicians also had been very concerned that I would die, but was then able to point out that each day I was a little better than the day before, and that they were cautiously optimistic that I would survive. This open exchange was very comforting to me and I did not again during my illness have such a compelling need to discuss these issues. However, adding to the total misery of the situation was the never-ending anxiety and resulting depression over my long-term prognosis. Even after it became clear, even to me, that I would survive, it was by no means clearly to any one whether I would be more than a respiratory cripple.

I cannot leave this discussion without acknowledging the tremendous support provided by my wife. While she was pregnant, and ultimately delivered our baby alone, by natural childbirth, four days before I left the hospital, she nonetheless was able to give selflessly throughout my ordeal. Because she had been an intensive care nurse herself, she was what the nursing staff termed a 'good visitor' and thus was allowed to stay after hours. I became totally convinced of the importance of a critically ill patient having his family with him for more time than the negligible visiting hours allowed in most intensive care units, and subsequently, have worked hard to get visiting privileges liberalized in our hospital.

Conclusions

I came away from this experience with great concern about who should receive the type of heroic effort which saved my life. I was naturally very grateful that everyone had worked so intensively to get me through it, yet it was obvious that the patient pays dearly, both physically and emotionally, in such a circumstance. Thus it seems clearly that for the patient who cannot get better by virtue of a diagnosis of end-stage malignancy, or other terminal disease, this type of care is totally inappropriate. I had many conscious thoughts that living was not in itself paramount and that maintenance of dignity and quality of life are truly valid concerns.

Accordingly, in the end, to me the two biggest decisions concerning the respirator are whether to use it at all and, subsequently, when to turn it off if the patient is not salvageable. However, cessation of an aggressive approach does not mean cessation of 'intensive care'. It does involve, though, acceptance of different goals, i.e., comfort for the patient and sensitive support for the family. These lessons from my personal experience led to my becoming involved with the hospice movement, which was just beginning in the United States at that time, for it was clear that the hospice philosophy was much in keeping with these concepts.

I would like to think that my experience has helped me to be a better doctor in a number of basic ways. I hope, and trust, that I now find it easier to listen to the patient. I no longer use machines and other intensive supportive procedures simply because they exist. I am able to talk more easily with sick people now that I have been there, and I understand that these patients are preoccupied with the fear of dying and want to talk about it. I am much more liberal with the use of morphine, when indicated, and can accept comfort as an end in itself. In short, I am able to deal better with the fact that some patients should be allowed to die quietly, with dignity, and without machines.

So, my final message is that we must not become a battery of specialists rendering superior *treatment* while *care* is absent. The patient should be the *beneficiary* of what we are doing, and not the *victim*. We must always keep our perspective, and not get lost in the maelstrom of our technology. We must always keep track of where we are going with our machines, not only medically and scientifically, but also economically, legally, morally and humanly.

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APPENDIX 4

OCTOBER 15, 1985.

Mr. Chairman, in order to help ensure that all sides of this issue are represented, I would like to present this statement by Doctors for Life written by Dr. Anne E. Bannon and Dr. Joseph R. Stanton.

Dr. Stanton was the witness who was unable to testify due to the limited time available for the televised hearing.

PARICK L. SWINDALL,
Member of Congress.

DOCTORS FOR LIFE,
St. Louis, MO, September 30, 1985.

HOUSE SELECT COMMITTEE ON AGING,
U.S. Capitol,
Washington, DC.

HONORABLE MAGISTRATES: We addess you in behalf of Doctors for Life. We have been informed that you are holding a hearing on Death with Dignity and the Living Will. Each member of Doctors for Life is committed to both life and death with dignity.

We wish to be recorded as opposing formally legalizing the Living Will because of inherent dangers in that instrument.

We hold:

(a) That the living will gives no right to the competent patient that the person does not already possess.

(b) That there is no "right to die".

(c) That death is a genetically inbred inevitability, inherent in the very humanity of every individual member of the species homo sapiens.

(d) That dignity in dying and in death is not created or conferred by a printed piece of paper, by legislative decree, or judicial fiat.

(e) That for the human person/patient food and water (nutrition and hydration), warmth, competent and compassionate medical and nursing care and hygiene are basic human rights not medically discretionary items.

(f) That such dignity as exists in dying and in death is never lost if the patient/person is cared for with the respect due to the dying human person.

(g) That the existence of a living will signed in a time of health without informed consent as to the illness, in which it may be brought to bear may in fact deprive the incompetent patient of what would be the appropriate treatment based on the appropriate best medical judgment of all the circumstances at that time.

(h) That is not a quantum leap from the "useless eaters" of the 3rd Reich to the "biologically tenacious individual", the "*chronic vegetative state*" and "incapability of return to cognizant and sapient behavior" as some ill and incompetent Americans have already been referred to in court decisions, legislative hearings, and in American medical and ethical articles.

(i) That attempts to broaden the definition of "terminally ill" from "imminently dying" to "when death may be expected in a year or so" creates a one size fits all definition that may be applied to almost any person over a certain arbitrary age.

(j) That in states having a living will on the books five years and longer, *there exists no documented evidence* that it is either widely utilized or that it solves the problems. Indeed, there is evidence to the contrary.

(k) That were the uniform living will law enacted, it puts a tool in the hands of those who in the name of cost cutting and utilizing scarce resources, might deprive aged and dependent patients of their basic constitutional right to life. The demographic factors already locked in place clearly indicate that there will be increasing numbers of elderly as we move into the 21st century. They will be expensive to care for and sustain. The deck should not be stacked against them.

(l) That the chief forces propagandizing for the living will are the Euthanasia Eduational Society, The Right to Die Society, and the Hemlock Society. We believe that *there exists no genuine urgency to create a uniform living will.* That such pressures as do exist come largely from such propaganda groups and their allies in the media stampeding legislatures like lemmings to fly off the cliff.

We draw to your attention the subjects of two Massachusetts Court cases, a) an the matter of Hier E84-592 and b) Brophy v N.E. Sinai Hospital. The patients, in both of those cases, are alive at the moment we write. Had either of these living patients signed living wills in the past, they would most probably not be alive today. Their continuing life was protected by existent law which allowed the appropriate best medical judgment to be determined and to be followed.

There is a growing concern that a uniform living will act may become a death warrant for aged and impaired Americans. Even now, papers are surfacing in the medical and ethical literature under titles such as "Against the Emerging Stream", Arch. Int. Med. *145* 129, 1985 by Siegler, M., M.D., and Weisbard, A.J., J.D. We urge careful attention to this counter tide even now emerging and growing. Thus far, only proponents of the living will have had media attention and that distorts perception from reality.

We suggest that your true warrant lies in the ideal expressed by Thomas Jefferson that "the care of human life and happiness and not its destruction is the first and the only purpose of good government." We ask fidelity to that warrant. We further request caution as you proceed and openness to the real concerns enumerated in this statement.

Indeed, each of us and others of the Board of National Doctors for Life would be pleased to appear before you and testify at any time.

Respectfully,

ANNE E. BANNON, MD., F.A.C.P.,
President, National Doctors for Life.
JOSEPH R. STANTON, M.D., F.A.C.P.
Member, Advisory Board, National Doctors for Life.

APPENDIX 5

American Association of Homes for the Aging,
Washington, DC, October 28, 1985.

Hon. Edward R. Roybal,
Chairman, House Select Committee on Aging,
Washington, DC.

Dear Chairman Roybal: The American Association of Homes for the Aging (AAHA) commends you for addressing a most sensitive and thought-provoking issue in your October 1st hearing, "Dying With Dignity: Diffilcult Times, Difficult Choices." As an Association representing over 2,700 nonprofit providers of housing, health care, long term care, and commuity services for the elderly, we are keenly aware of the complexity of this issue and the overriding need not to lose sight of the terminally ill person's total care needs—psycho-social and spiritual as well as medical—which require patient and family involvement and compassionate caregiving.

We are very pleased to have this opportunity to share with you a speech by Monsignor Charles Fahey, Director of the Third Age Center at Fordham Univesity, on "The Quality of Life . . . The Dignity of Death." Monsignor Fahey, a past president of AAHA and long-time member of the Association, presented this speech to the AAHA membership at the Association's Annual Meeting in San Antonio last year. We believe that this speech presents an important framework for discussion and public policy decision making regarding death and dying—discussion that must extend beyond the legal implications of medical technological and encompass the ethical and moral dimensions of caring for the terminally.

Thank you again for your attention to this most important issue.

Sincerely,

Dean Sagar, *Director of Governmnet Affairs.*

Enclosure.

The Quality of Life . . . The Dignity of Death[1]

It is a pleasure to be here with you today. However, the subject of the quality of life and the dignity of death is not as easy one. What I propose to do today is to present to you a challenge and general framework within which that challenge might be dealt with. I take this approach because there are no easy answers or prescription for behaviour in addressing death with dignity. Rather, I am going to give you an overview and talk about it not ever being this way before. I am going to speak about the competence of AAHA generally and your particular facilities. I'm going to talk about the necessity of both discernment and action, and about the publicness and the privateness of death. I am going to speak briefly about the interaction of law, ethics, morality, and values. I am going to speak specifically about the typography that we must deal with inevitably. Then, I am going to make a modest proposal for you as a group, for us as an organization, and for your individual facilities. I'm going to speak to its importance and to its possibility. That's a large agenda and it's complicated; yet, there is no way that we can deal with this agenda without nuancing it and without putting it together with its different, various elements.

I begin with the theme that some of you have heard me give before but not precisely in the same way because it has never been this way before. Indeed, we cannot put new wine into old wine skins, or sew old cloth with new thread.

We need to take a look at the reality of today, and to take our considerable wisdom, knowledge, and commitment and deal with today and tomorrow's reality. It has never been this way before because of the sheer numbers that are involved. It has never been this way before because we have been successful in decreasing morbidity and mortality for every age cohort, but we also have a secondary and unintended effect—a rise in both the incidence and prevalence of chronic disease among many of our people. We always have to be careful to remember that among the old, the frail will always be the minority; yet, it is a minority which is increasing both in numbers and significance. So it's never been this way before in terms of the type of conditions that people face and the degree of frailility and vulnerability. At the same time, we have seen technological advances that have helped in this process, not necessarily of prolonging life span materially, but of prolonging life expectancy.

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[1] This is an edited version of a speech, written and presented by Monsignor Charles J. Fahey, Director of the Third Age Center, Fordham University, New York, NY, at the American Association of Homes for the Aging's 1984 Annual Meeting in San Antonio, TX on October 29, 1984. Monsignor Fahey is a past President of AAHA and a long-time, active member in the association.

Within this context we also find ourselves in a culture that emphasizes the centrality of medicine. So effective has medicine been in dealing with things that assault the human personality, that we have ascribed to medicine—its practice and those who practice it—a central role in managing and dealing with almost every hurting human condition. Adding to this is the new reality that we face in our country, the realization that the sky is not the limit; rather, we will have to make painful choices and decisions in regard to the allocation of public resources, societal resources, and we will face excruciating kinds of decision making processes through which these resource allocation decisions will be made. We have always had to make these decisions, but it is one thing to make them within the context of a burgeoning economy and a growing amount of resources available to us, but quite another to make them in the context of the greater realization that we must be more careful stewards of the limited resources we have available to us. Finally, in all of us, we also have an explosion of knowledge and more and more specialization in different ways of coming at human hurt. So, indeed, it has never been this way before.

The second point I draw to your attention is consciousness raising in order that you and I might appreciate ourselves. The institutions of which we are part and the general movement of which we are a part are represented here today. Very simply, there is no one in the history of the world and no one today in our country or abroad that constitutes more actual involvement with death than do we. Every one of our facilities, often implicitly but oaccasionally explicitly, recognizes that we are people who deal with death continually. Indeed, it is an essential part of our coming at the social components of care that we not only celebrate life in its fullness, but we also recognize the reality of death and the dying processes. We go about it more or less well. I suppose the challenge that I will come to at the end of my presentation is that which can only be made to a group that is still young and growing in its self-awareness and thus growing in its maturity. As a movement formally, at least brought together by AAHA's formation only twenty-three years ago, it is appropriate for us to recognize that we have a responsibility in the community not only in public policy, and in advocacy for specific for public programs, but also that we are involved with ideas, culture and the air we breathe. Even as we are influenced by culture and societal norms, it is important that we take our rightful place in influencing them and having something to say from our experience.

I want to be careful how I say this, but by and large all of us in the direct service area of the not-for-profit field tend to suffer from a kind of false humility. We know more than we realize. While dependent upon our scholars and researchers, we too are part of the public policy process. We contribute to it and are influenced by it. We are part of society. But even as we are part of these things, we must influence them, be in dialogue with them. Just to take the religious sector of which many of us are a part, many of our various traditions have views in regard to death. Frankly, although death has always been with us, death is materially different today than it has ever been before. We must speak to theologians and religous leaders from the praxis in which we are all engaged. Indeed, we must listen to scholars like Kubler-Ross and others, but our collective wisdom must inform scholarship and programs as well.

I therefore bring us to the third point with two elements: discernment and action. Let me pause for a moment about the word discernment. I suspect it has a little bit of a religious connotation and I actually mean it in that way. All of us are familiar with research and we must be involved with research. However, we do it inadequately whether at an institutional, state, regional, or national level. Somehow the rich experience that we have is not brought together sufficiently so that we might be able to understand actually what is happening and to learn from our collective experience. But, I am now talking about a process that is deeper, broader, and more intense than that merely of research. We in effect have a new reality. It is constituted by the prolongation of the life span, by increased longevity, and by the knowledge and technology we have. Put those all together and that is something new, it has not been this way before. Again, if I may speak out of a religious tradition that I think most all of us share, we could say that in effect, God's revelation continues as long as there is something known about the stars above or intrapsychic functioning or our social functioning. Or put it in a secular term if you will research, or in a more religious context of discernment. We must be concerned about a process of understanding the reality of death in this time, to try to understand how we come about it as persons and individuals, as facilities, as a society, and as a nation. In all of this, we are not talking about others, we are talking preeminently about ourselves.

This brings me to the fourth point about death and some notions in regard to it. Death is not an easy subject; it is not easy to deal with it out there. It's harder to deal with it within ourselves, whether the within ourselves is the tears we weep for a parent, spouse, a child, friend, a person with whom we worked. And all of us have shed those tears even as we have struggled with it intellectually. There would be a dichotomy that I would set up that is somewhat faulty but is nevertheless useful for our discussion. One can look at death as intensely personal, always individual, and always private. Indeed it is all three. However, we can also look at death and say that it is always social, always involves others. There are generic elements to it because we share the common human nature and therefore there is a universality about it.

We can also say that it is public because it always involves people and often it involves resources in one way or another, to which strangers have contributed. There is a great temptation in our society to focus on one or the other of these two extremes—to make death an entirely private affair or to make it an extremely public affair. And I say we cannot do either. You know in moral reflection, just as in all the rest of human existence and in the public sphere as well, it's always so easy to go for solutions that are black or white, yes or no. But all of human existence, including moral kinds of reflection, involves the area of greys. So we affirm the mystery of life, the death of personal emotion that is involved with the circumstances of death, and we recognize that theology and philosophy are preeminently there to serve us as individuals in dealing with the mystery of life and death and suffering. And indeed we always affirm that it must be something that has lived within the private and personal context of families and friends.

But even as I affirm the latter, we begin to see the public nature of it. It is social in that it always involves family, friends or others, or helpers, if you will, like you and me. Death in our culture almost always occurs in social institutions, in hospitals or in nursing homes. It rarely happens now in one's own home. Government has a prima facie responsibility in regard to the protection of life. By its very nature, government is pro-life, protecting those who are most frail and vulnerable. And in a more subtle, yet important way, whether or not government uses its taxing power, and how it uses it, is instrumental in many instances of whether people will have life or death. Surely government has the responsibility in regard to those processes around decision making at least. Therefore, we must deal with both the private and the public, both the personal and the societal, both the individual and the generic, and all are part of our reflection in regard to death.

My fifth major point is a tough one, but I must deal with it for a moment. It's about the law, morality and ethics. I think that it is very important and let me start with the word "values". Values is not an unambiguous word. It is a word that is a way of describing reality; it doesn't necessarily mean something good. So, the people who are involved in sociology, the number crunchers like myself, are comfortable with values. We tend to go out, look at things, and measure how people actually function. We say that's normative because that is what they are doing. We also will ask people what they think. This also becomes the way we look at behavior. Thus, we are able to identify perhaps what values groups of people hold, but it begs the question of what the values ought to be in the first place. This is where both morals and ethics come into play.

Let me take a moment to describe what I mean by those two words. Morals and ethics are a way to look at behavior; they're looking at the oughtness of personal behavior of individuals, the oughtness of interpersonal relationships. They're talking about the relationships of groups with individuals, about society and individuals. And more recently, we recognize they are talking about the acts of government as well. There is a moral and ethical quality in all of these areas. Each is a discipline; the area of morality tends to come out of a religious tradition; the area of ethics comes out of a philosophical tradition. De facto, as we put them together, they are intertwined. Each religious tradition has a view of reality. And as soon as we have a view of reality, particularly one that comes from reflection on a relationship with the supreme being, it has implications in terms of our behavior. Ethics, on the other hand, is a discipline, with its own norms and its own way of going about it, but it takes the common human experience and puts a value upon action in terms of its oughtness, in terms of that which is better, and that which is worse. There can be a great deal of confusion involving differing perspectives on moral and ethical values. But I would affirm to you that the question of reflection on moral and ethical values is critical in our society, and it is different than law.

Note the difference: law is something that is extraordinarily important in our society. However, by its nature, it is generic and it is broad. It tends to serve as a least common denominator and it cannot require that which is better or that which is good. It has nothing to do with virtue. Allow me to suggest an example of the difference. We can conscript young people to serve our country in the armed services—that's the legitimate area of law, but law cannot say to us that we must be patriotic. That's in the area of morals and ethics. Morals and ethics talk about attitudes, and internal convictions while, by and large, law is concerned with behavior and has little to do with intent.

On the other hand, at the very heart of morals and ethics is intent because that, after all, is what gives us values as human beings. It influences how we act and what our intentions are in terms of good and evil. Therefore, as individuals and as professionals and as group providers, as state associations and as a national association, we have two-prong responsibility. We need to develop a moral and ethical perspective in regard to death, dying, and those who are in the process. We also need to be engaged in the question of how much law, whether state or federal government should be involved, relative to death and dying.

Sixth, what I am saying is that I think this is the moral territory that we, as a societal group, have to reflect upon and investigate. I have identified five general areas that constitute the territory or typography for discussion and reflection. First, when does life end; that is, the determinaton and definition of death. The second area involves the process of dying for those who are clearly near the termination of life. Third is the question of those who are severely disabled who would otherwise survive except their various bodily systems are weakened and are vulnerable to disease, and the way in which we go about either preventing the disease or intervening therapeutically, so that the disease will not cause death. Fourth is the area of decision making in all of the above three. Fifth, and not the least important by any means, is the question of supportive interventions, of a caring community if you will, in regard to those who are dying. I would like for a moment to reflect on each one of these briefly.

First, note there is a difference between the definition of death and its determination. In terms of defining death, we do it only for public purposes. Death is a mystery; no one knows when someone dies. Nobody knows. The only clear indication of death is actually when putrification comes into play. Who knows what tomorrow will bring. But for thousands of years, common law, the practice in our facilities, and often statutory law have reflected one test, the cessation of breathing, of heartbeat as being the sign of death. Indeed, that has been sufficient and necessary to bring about a formal determination of death for public reasons and also for interventions. On the other hand, everytime we make a discovery we find that these kinds of definitions may not be all that certain. CPR, for example, has brought into play the ability to recussitate people. So the old test we all held so firmly became a little more tenuous in terms of its universality and its applicability. Yet, we have all experienced the excruciating kind of process in which we maintain the heart, the lungs and circulation, but what we don't maintain is the function of the brain. And many jurisdictions have in effect said that for public purposes, intervention need not go beyond a certain point; that is where there is total and irreversible brain functioning of the total brain. This is accepted by and large by ethicists and moralists as well as in many states. Frankly, I suspect that the determination and definition of death is not the area of greatest challenge for us.

My second point is where we do have problems and enormous challenges and that is in the dying process itself. There are always two questions here and I want to defer on the one about decision making. When we attend conferences on death and dying regarding the legal and ethical implications, it fascinates me because the people presenting are doctors and lawyers who, by and large, focus on competency, due process, and how you avoid liability. Very few of them are talking about the basic oughtness of death and dying: how are people informal, how am I informed, how is my family informed about what ought to be done in the dying process. This is really the question that faces us. In a book by Dr. Clements, there is an article by theologian John Bennett in which he notes that by and large, religious tradition which has addressed this issue most extensively is the Roman Catholic out of the declaration of Pope Pious XII which say that, one way or another, the concepts of ordinary and extraordinary means have tended to find their way into ordinary practice. That is, you ought to do what is simple to do and you don't have any obligation to do that which involves extroardinary effort. The only problem is that what used to be extraordinary, today becomes ordinary. We have seen a development and an evolution not only in Catholic moral theology, but generally speaking in many of these conferences, of a greater specificity in the area of extraordinary. It no longer solely involves discussion of the complicated procedures and technology, but it also involves considerations such as:

Is it there merely to prolong life wihtout anything more (a person not being capable of any cognition)? Does it involve the alleviation of pain or doesn't it? Is rehabilitation possible or isn't it? Is there a cost involved, an economic cost to the individual, to the society, are there other kind of costs? Is there convenience involved to the individual or to others? The moral equation is never easy; it isn't a mathematical formula, it's a human judgment. What usually is involved is not a question of good and bad, but a conflict of two goods. We must struggle with that but the little time we have available makes it difficult for me to distinguished it too well. I would merely note two specific areas of special concern to us. One is in the use of drugs that can be foreseen to shorten life, but on the other hand, can be seen to alleviate suffering. There seems to be a consensus that such a use and intention for the terminally ill is within the context of good morals and ethics. The more difficult issue is the question regarding the noncompetent individual, totally incapable of any self-care, in terms of how we provide food and water, particularly in the instance of having to provide it intravenously or through tubes.

The third area of this typography has to do with disabled persons and their dying. The state of Minnesota and others have tried to codify this. Whether it be a disabled child, a demented person of any age or someone who is very old, they are not dying. However, the very nature of the dementia or the disability renders such a person particularly vulnerable to other assaults from various natural sources, such as the immune system isn't as strong. Critically in this area, from an ethical point of view, is the question—what should be done in this instance? Is it necessary to provide corrective kinds of therapies, preventive and prophylactic kinds of therapy? Is it necessary when disease comes to intervene in the lives of these individuals? In this case, who ought to make the decision, and what should be the role of law?

The next area I draw to your attention is the question of decisions around death. We have to issue of the person himself who is competent and all those things that have to do with instrumentalities before the person becomes incompetent and how they bind us. With regard to the incompetent person, the issue involves the role of family and all these other things, or those who stand in the place of family, the role of the conservators, the courts, etc.

Again, all the conferences tend to focus on this and I won't belabor them. Another issue regarding decision making is one that I don't think we fully recognize. It is the issue of the group provider and its decisions regarding various issues of dying. Facility A, B, or C is also involved, not only the individual, family and doctor. As soon as a person walks through the door of a nursing home, hospital, or in the context of a home health agency, certain responsibilities are both explicit and implicit about that facility itself, its moral stance and its views. What is the moral stance in regard to death and decision making of the facility and how does it engage itself through its practices, policies, and procedures? In addition we need to look at the interaction of professionals within a facility. At least some, if not most, cases being brought before the courts at the present time in the area of appropriateness of treatment are being brought by one staff member of a facility against another, the nurse versus the doctor versus the adminstrator. How one develops a corporate culture in which all are involved and to which all are held accountable is an important issue in which we all need to be engaged.

Finally, with regard to decision making is the fact that, frankly, many of the decisions regarding the dying and our capability to deal with them will be made in Washington or state houses throughout the United States. These decisions are about what we will spend our Medicare and Medicaid money on. Indeed, decisions affecting us are also being made in Blue Cross plans and private insurance, as determinations are made regarding what we will pay and will not pay. Sometimes it is spoken of as upstream violence. Whatever it is, these areas have great implications for the range of choices we have at the local level and what we do or don't do are fundamentally a result of the values we articulate as a people. Pulbic policy doesn't result from a moral process but from a political one. However, it is the values of families, individuals, and trade organizations that become part of the political process, evolve a statute, a regulation, a reimbusrement policy—all of which take on a moral quality and are subject to the question of moral analysis in terms of the goodness, the badness, the preferability of choosing one path over another. We must do that as well.

The last area of moral territory involves the question of how do we let people die with dignity within the context of our moral decisions. I believe we've done some things in this area as an organization, but I think we need to do more. You know that every nursing home is a hospice to some extent and again, hospice has come into being out of revulsion due to the high technology and the fractionalized way we do things. We need to develop a body of knowledge about the actual process of achieving death with dignity that is represented in the field by AAHA which will not only inform ourselves but also our brothers and sisters in the broader community. I'll pick on no other group except the clergy. Frankly, Fordham has engaged in some examination nationally of pastoral care of the most frail and most vulnerable which discloses that there are voices in the wilderness, there are charismatic individuals, there are some people who bring tremendous gifts to bear with those who are dying or those who are disabled. But they are the exception, not the rule. By and large, the pastoral care for people who are frail and vulnerable is poor, even in religiously oriented facilities and programs.

This leads me to my conclsuion and I would make a proposal that hopefully is not too modest, yet which I think is extraordinary important, and is based upon all I said before. Death and dying are extraordinarily important events in the lives of us all—personal, individual, and private. But inevitably death and dying are public; they are societal; and they involve groups. We may wish it to be different, but in our interdependent society and the litigious world in which we live, with the kind of ways we solve problems, this issue is in the public forum. And I feel the public forum will be improverished if AAHA, as a movement and an organziation, does not strive to develop a position and perspective on all of this moral typography about which I've spoken today. We have said it in the past and we say it again here, every AAHA member should state its values, its beliefs, its philosophy, its conviction, not only in regard to life but regard to death. And there should be found in each of our statements a purpose, an articulation of our perspective of how we deal with death in our facilities.

Indeed, there should be an articulation in policy and procedure, and indeed a process for reflection so that we hold ourselves accountable to our own constituency, our residents, and to the broader community in this regard. Frankly, I feel that there is far more consensus than division within the House. I think that this is extraordinary important for two reasons. It is important because of the subject itself. We see that the nature of the law, although developed and implemented by well meaning legislators and government administrators—many of whom, in my judgement, are our heroes—is clumsy, unfeeling, and professes to be value free to a large extent. But, of course, it isn't. Can you imagine today trying to write the Constitution or the Bill of Rights? We hold these truths to be self evident that all people are created equal endowed by their creator with certain unalienable rights. Today, we simply couldn't do it in our culturally pluralistic society. However, we as an association can work together to address the process of death and dying.

I would foreclose with this last thought. Not only would this action be significant as far as death is concerned, but it would be significant in terms of the interaction of the private and public sectors. Frankly, I am appalled by the politicization of religion and moral values and suspect that there will be a revulsion of this in our society as a whole. Yet, whether it be war and peace, the solution to Medicare and Medicaid, or the national debt, we are going to be faced with the kinds of critical decisions in the future that require of us absolute moral reflection and synthesis and critical kinds of thinking and discernment. We must understand what we want the Social Security system to achieve and how it is going to do social justice at the heart of it. We must be involved in all of these areas from a moral and ethical point of view. Our society desperately needs an experience in which thoughtful and caring people come together and develop a consensus on some issues and, where consensus is not possible, develop a civil way to discuss areas about which we disagree. Oliver Wendall Holmes said that democracy is predicated upon people who act ethically. We can never be satisfied with law alone to govern our behavior or we would have a fascist and totalitarian state. Tough cases make bad law. Many tough cases make for oppression. We are in a field that often has seen those aphorisms realized. John Courtney Murray, the distinguished Jesuit who had so much to do with Vatician II's declaration of regligious independence, noted—in "we hold these truths"—that democracy presumes a virtuous people; and virtue is not a product of law, but law is a product of virtue. Sure, we make mistakes at times, but by and large we are a virtuous people. I have great confidence that we can meet this challenge because you are people who care and love and, indeed, you are people who can struggle together with these issues of the quality of life and the dignity of death and share the results with our whole society. Thank you.

APPENDIX 6

NURSING HOME ACTION GROUP,
St. Paul, MN, September 28, 1985.

Re. October 1, 1985, Hearing on "Dying With Dignity"

Mr. GARY CHRISTOPERSON,
House Select Committee on Aging,
Washington, D.C. 20515

Dear Mr. Christopherson: The Nursing Home Action Group has just learned that there will be testimony October 1, 1985, before the House Select Committee on Aging on the topic, "Dying With Dignity."

We are very concerned about medical neglect and abandonment of persons with severe physical or mental disabilities. We have seen instances of discrimination against patients on the basis of their age. Vulnerable individuals sometimes have been allowed to decline into so fragile a physical condition that it appeared appropriate to stop treatment. In fact, some nursing home and family conditions may aggravate this problem. (Please see May 10, 1985, Report by the Chairman of the House Subcommittee on Health and Long-Term Care.)

Because we have just learned of the October 1 hearing and understand the topic is quite broad, I am enclosing copies of the following for submission as written testimony:

1. Statement of concern about the "Uniform Rights of the Terminally Ill Act," August 1985.
2. Statement of concern about a living will bill which was tabled during the 1985 legislative session in Minnesota.
3. A Commentary about death-allowing care for persons with severe mental and physical disabilities, 1984.
4. Resolutions by disability rights groups against limitation of treatment based on disability, 1983, 1984, 1985.
5. Commentary about the matter of Karen Ann Quinlan.

Thank you very much.

Sincerely,

JANE D. HOYT, *Chairperson.*

Enclosures.

NURSING HOME ACTION GROUP,
St. Paul, MN, July 30, 1985.

Re (a) Multiple concerns about the proposed "Rights of the Terminally Ill Act" (August 1985 draft); (B) Request for delay of final consideration of this act

RICHARD C. HITE,
Chairman, Drafting Committee on the Rights of the Terminally Ill Act, Minneapolis, MN.

DEAR MR. HITE: Please give consideration to the following list of concerns about the proposed "Rights of the Terminally Ill Act." Because of these concerns, we wish to request a delay in final consideration and voting on this act proposed by the National Conference of Commissioners on Uniform State Laws.

(1) *The title of the proposed act is a misnomer.*—This act is called "Rights (plural) of the Terminally Ill"; however, there is basicially only one "right" stressed here, namely, the right to have treatment withheld. There is no mention of ensuring comfort and alleviation of pain, of continued high standard of nursing care, etc. for the dying patient. Omission of such rights is one of several ways in which this proposed act seems not to focus on protection of the patient.

(2) *There seems to be some confusion of concepts.*—On Page 1, about half-way down the first paragraph in the Prefatory Note, is the sentence:

"Its (the act's) impact is limited to treatment that is MERELY LIFE-PROLONGING, and to patients whose terminal condition is irreversible, whose death will soon occur, and who are unable to participate in treatment decisions. (Emphasis added.)

Surely what is meant is "MERELY PROLONGS THE DYING PROCESS," which is conceptually and, from a legal standpoint, significantly different from what is stated in the proposed act.

(3) *The role and rights of nurses are given less consideration than physicians and facilities.*—On Page 1 at Paragraph 3 (3) of the Prefatory Note, there is no mention of nurisng staff—just of physicians and of facilities. It seems only fair that nursing staff should be accorded equal rights and consideration with physicians and facilities in such legal matters.

(4) *There is an erroneous and confusing definition.*—In Section 1, Definitions, at (4), it is stated:

"LIFE-SUSTAINING PROCEDURE" means any medical procedure or intervention that, when administered to a qualified patient, will serve only to PROLONG THE DYING PROCESS," (Emphasis added.)

This definition of "life-sustaining" is inaccurate and confusing, giving a meaning opposite to what the words actually mean. it would seem more accurate to have, for example, a definition for "prolonging the dying process." (This problem occurs also in Section 8 at (d).)

A "life-sustaining procedure" sustains life. Insulin is a life-sustaining medical treatment for diabetes, and dialysis is a life-sustaining procedure for renal failure—but they would not be considered "life-sustaining" measures under the present definition in the proposed act, which would be ridiculous.

A particular danger is that many serverely disabled people (with, for example, MS, Alzheimers, stroke, spinal cord injury, etc.) could be mistakenly considered to be in a "terminal condition" under Subdivision 8 of the Definitions because they (1) have an incurable or irreversible condition and (2) might die within a "relatively short time" if they were not given antibiotics or assistance with hydration which would both be considered "life-sustaining" procedures in the ordinary, dictonary meaning of these words—but not by the definition in this proposed act.

Using Subdivisions 4 and 8 ("life-sustaining procedure" and "terminal condition") to define each other only compounds the confusion as to what the terms mean.

(5) *The Comment section on Page 5, paragraph 3, under Definiitons states an intention which is omitted in the proposed act.*—It is stated: "Though the Act intends to err on the sie of prolonging life, . . ." Nowhere in the proposed act itself is any such intention made explicit.

(6) *The euthanasia disclaimer, which comes almost at the end of the proposed act, should be more prominent.*—Because of widespread concern about euthanasia, and because of the drafters' stated intention that this proposed act "err on the side of prolonging life," it would be well to give the euthanasia disclaimer much more prominent placement, such as at the very beginning.

(7) *The provisions for executing a declaration are too simplistic.*—Considering the very important consequences of this declaration, it is not protective enough to allow the comptent adult to execute a declaration at "any time," with no determination that the individual was making the decision without duress and was not under the influence of chemicals or clinical depression.

(8) *Similarly, there is need for some specific qualifications for the two witnesses.*—With absolutely no qualifications for the two witnesses, and no determination of the condition of the declarant when he/she made the declaration, there are virtually no protections against faulty or uniformed decisionmaking on the part of the declarant.

The comment section (Page 8) attempts to justify this failing in the interest of simplicity and of "relieving" physicians of a responsibility to help determine and ensure that decision making was done with proper cautions. This failing, this expediency, gives consumers the impression that a primary objective of the act is to protect physicians and facilities.

(9) *A definition is needed for "actual notice.*—In Section 7 at (a), it not not clear what is meant by "In the absence of ACTUAL NOTICE. . . ." (Emphasis added.) What is an "actual notice?"

(10) *Definition (8) incorporates an unenforceable standard.*—The time standard of the proposed act, i.e., "a relatively short time," is too loose to be enforceable. Such a standard is hopelessly subjective and would permit overly wide variations in professional opinion and practice.

The closer a patient is to death, the more clear becomes the expected time of death, and the less possibility there is for misdiagnosis or inaccurate prognosis. We would urge therefore that a much more definiite time frame be used, such as "two to three weeks in the professional judgment of the attending physician." (Please see, for example, the "Do-Not-Resuscitate" guideliens of Beth Israel Hospital in Boston, a teaching hospital of Harvard Medical School.)

(11) *The proposed act should provide that the patient must be informed when his/her declaration goes into effect (unless documented as medically contraindicated to inform the patient.*—According to the comment on page 10 about Section 4, it is only "assumed" that the patient will be informed. This is NOT protective enough of the patient's right to know.

(12) *A second opinion should be given with respect to concurring with the diagnosis of terminal condition.*—Again, this is simply to ensure the greatest protection for the patient who is expected to die. If there is good reason for not being able to obtain a second opinion, that reason should be documented in the medical record.

(13) *Consultation merely with the patient's family is very limiting.*—There are many patients who have no families, or who are estranged from their families. It may be that there are close friends or other advocates of the patient's choice who should be considered for possible consultation in medical decision making.

(14) *Section 5 (c) has a rather low standard for continuing life-sustaining procedures.*—"Probable."

(15) *Nutrition and hydration are considered in the proposed act (SEE Comment section, page 11) to be the equivalent of medical procedures despite a lack of universal consensus on the issue.*—Many patients have little knowledge of legal and academic issues of medical ethics before having to make such decisions. Thus, it would be more clear, more reasonable, and more protective of dying patients' rights if the language of the proposed act explicitly provided for stating wishes about nutrition and hydration separately from what are usually considered to be medical treatments.

Furthermore, since this proposed act is about rights of the terminally ill, why does it "NOT PROHIBIT any action considered necessary by the attending physician for comfort care or alleviation of pain," (emphasis added) rather than mandating these basic rights?

(16) *An additional immunity is needed.*—In Section 7 there should be a fourth explicit immunity—for "A caregiver who refuses to comply with the declaration in accordance with the provisions of Section 6, Transfer of Patients." Otherwise, the immunities fall only to those who hastened death, not to those who in good faith refused to go along with the declaration and followed the provisions of of Section 6 instead.

(17) *Clarification is needed under Penalties (or under General Provisions).*—Rather than merely "assuming" at page 14, second paragraph of the comment section, that felonious conduct is clearly covered in other laws of all states, it would be more protective of patients and more clear to state: "Nothing in this act shall be interpreted to supercede or take the place of any criminal liabilities for intentionally or negligently causing the death of another."

Thank you very much for your attention to this request for reconsideration of the proposed "Rights of the Terminally Ill Act."

Sincerely,

Jane D. Hoyt, Ed.M.,
Chairperson.
James M. Davies, LPN, JD,
Vice Chairperson.

Nursing Home Action Group,
St. Paul, MN, August 8, 1985.

Re Reasons for voting NO to the "Rights of the Terminally Ill Act."

Members, National Conference of Commissioners on Uniform State Laws,
Minneapolis, MN.

Dear Commissioners: The NCCUSL, meeting as a whole group, has spent over eight hours deliberating on the proposed "Rights of the Terminally Ill Act." It is clear that good questions remain about the protectiveness, clarity, and use of this proposed act.

Please consider voting NO when this act comes for the Voting by States this afternoon, for the following reasons:

(1) This proposed act does not intend to promote mercy-killing or euthanasia (Section 9, Subd. (f); nonetheless, the concern remains that euthanasia may be the consequence of the proposed language.

The definition of "terminal condition" is far too broad. A particular danger is that many severely disabled people (with, for example, M.S., diabetes, spinal cord injuries, stroke, etc.) could be mistakenly considered to be terminal because, under this proposed act, they (a) have an incurable or irreversible condition and (b) might die within a "relatively short time" (an unenforceable time standard) if they were not given what are ordinarily considered "life-sustaining treatments."

How long may the dying process be prolonged before it is considered to be "only" prolonging that process? There might be the risk of prematurely cutting off someone's life by months or years.

(2) The provisions for executing and for witnessing a declaration under this proposed act are very consequential and very expedient, yet not very protective.

Please vote NO so that this proposed act can be more fully considered with a view toward balancing patient and physician autonomy and protection. Thank you very much for your attention to all the concerns raised by the proposed act.

Sincerely,

JANE D. HOYT, *Chairperson.*

STATEMENT OF JANE HOYT, CHAIRPERSON OF THE NURSING HOME ACTION GROUP

My name is Jane Hoyt. I am chairperson of the Nursing Home Action Group, and I am active in several other local disability rights organizations. I wish to raise a few concerns about House File 1301, the Living Will Bill, but first I want it understood that we strongly support the Minnesota Patients' Bill of Rights and therefore support the first two sentences in the Policy statement of House File 1301, Subd. 2, (dated 3-20-85) specifying that competent adults have the right to control medical decisions about themselves. We empathize with the frustrations of patients and families faced with life-and-death decisions, and we understand the worries of physicians and hospitals with respect to malpractice.

Our concerns with this bill are—

First, and most important, in Subd. 7, the definition of "terminal condition," is confusing. A condition such as cancer may be terminal, yet death may be not at all imminent. Because this bill pertains only to the situation in which death has become imminent, the word "IMMINENT" is most important and needs to be better defined. The word "imminent" should be defined to mean some specified short period of time. We would like to recommend the definition given by Dr. Mitchell Rabkin in the August 12, 1976, New England Journal of Medicine: Death is imminent when the condition is irreversible in the sense that no known therapeutic measures can be effective in reversing the course of the illness, irreparable, and in the ordinary course of events, death will occur within a period not exceeding two weeks.

Furthermore, for the protection of all interested parties, every time the words "terminal condition" are used, they should be followed by the words, "and death is imminent." It is fairly easy to diagnose a condition as "terminal" but less easy to predict life-expectancy after the diagnosis. Imminency of death, if we consider "imminent" to mean a very short period of time, can be made with a more reasonable degree of medical certainty. The term "no recovery" has also been found to have a multiplicity of meanings, depending on one's view of disability.

Second, for the protection of both the patient and the physician, it would seem that a signed, written living will is most protective. The language at the end of Section 3 indicates the living will could be only oral, with the physician just noting in the medical record that the declarant had made an oral statement. Written, signed documents must be mandatory; though they could be dictated by the declarant and signed by a witness at the direction of the declarant as described earlier in Section 3.

Third, with respect to Section 5 (Revocation), we urge that the living will have an automatic revocation if not renewed within a specified time period, such as three years. Because of the importance of this document, it should be carefully reviewed from time to time, giving consideration to changes in personal values and medical technology.

Also, with respect to part (3) of Section 5, we are concerned about the patient who has no designated advocate, whose "living will" is not near at hand, and who cannot write. An expression of intent to revoke should become effective immediately if communicated to any person or caregiver, not just a physician; however if that person or caregiver is not the attending physician, it is a caregiver's responsibility to contact the attending physician immediately to communicate the patient's changed wishes so that treatment may be changed as necessary. The reason for this is that almost always nursing staff rather than physicians are in closest personal contact with patients.

Fourth, we are curious why nursing staff are not included under Sec. 7 (Transfer and Liability). Like an attending physician, a nurse may in good conscience not be able to comply with the declarant's refusal to accept treatment. It seems only fair that nursing staff should be accorded equal rights with physicians in this matter.

To illustrate the fact that persons may change their minds after suffering a presumed terminal illiness, I will cite a personal experience. My mother suffered a massive stroke in 1962. She was diagnose as terminally ill and imminently dying by very reputable doctors. The neourosurgeon stated that she would die even with surgery. My father asked that he go ahead and try the surgery if only to learn from the procedure (which has since become quite common). My mother survived the surgery and returned home for many years. There can be no doubt that she heartily interacts with her environment and enjoys life even now in a nursing home. In fact, the few times she has had the flu, she has stated that she wants her medicines and she wants to get well, that she does not want to die. When my father died 14 years ago, which was nine years after her stroke, I closed up my parents' house. In going through their papers, I was surprised to find the equivalent of an unwitnessed "living will, " which my mother had written some years prior to her debilitating stroke. In her living will, she made it clear that she wanted no "extraordinary" care if she were in a condition from which recovery was impossible—exactly as she was considered to be at the time of her stroke. I have no idea if my father knew she had written that statement. I do know that my mother strove hard to recover, did rehabilitate remarkably, and continues to participate well and happily in daily activities.

Finally, because "terminal condition" is so weakly defined in this bill, and because of our experiences, we are concerned about Section 6, Procedure Absent Living Will. Attached is an article written by an attorney and me, in which we explain concerns shared by disability rights advocates about the devaluation of life after disability. It is clear to us that many people mistake disability for illness. Because life is more complex after disability, many people—whether they are the patients or the relatives of the patients—may reject life-sustaining measures. The decision to forego or withraw treatment may be premature if the condition appears possibly "terminal" but turns out not to be. We hope that people will not write living wills because of ignorance or fear about life after disability.

Given the lack of clear definition of "imminent," the provisions in House File 1301 for writing one's own living will seem too lax, especially if applied to nursing home residents. We have much evidence of nursing home residents who have deteriorated due to neglect (such as poor management of their medications, lack of needed treatment, unpleasant psychosocial environment). These patients may appear terminal, and if neglected, be terminal. Also, nursing home residents are often under real or presumed pressure to behave in certain ways or to go along with caregivers' and family expectations. Because of this, the Nursing Home Action Group recommends that very careful documentation be made in a medical record before a facility complies with a resident's refusal of a treatment. (Please see the attachment at end.)

Our concerns about this matter are strengthened by court testimony in a local case and by a study reported in the April 26, 1984, New England Journal of Medicine, which stated that some doctors at a prestigious hospital declined to comply with their patients' desire for a "Do-Not-Resuscitate" order because the doctors believed patients with DNR orders tend to have less aggressive care from nursing staff, even though a DNR order in no way is intended to lessen care and treatment except in the event that breathing or heartbeat stop. Similarly, people may fear that the presence of a "living will" in their charts implies they do not expect the highest standard of nursing care. Our raising this concern does not negate the need for directives from patients, but stresses the need for every caution.

Also under Sec. 7, in Subd. 2 (Immunity from Liability), it would seem more protective for all interested parties to qualify "person" with the word "authorized," so that it reads, "An AUTHORIZED person who ORDERS the withholding . . . in accordance with . . . a living will . . . is not subject to . . . liability. . . ."

Fifth, we urge that the Prohibition statement, that "nothing in this bill be construed to condone, authorize, or approve mercy killing or euthanasia . . ." be given a more prominent placement at the beginning of the bill.

Thank you for your consideration of these concerns.

FROM THE NURSING HOME ACTION GROUP GUIDELINES FOR THE PROVISION OF MEDICAL TREATMENT AND NURSING CARE

Before a health care facility may comply with a patient's refusal of a treatment, there shall be detailed documentation in the medical record:

A. that the patient is legally AND clearly competent,

B. that the patient made the decision freely and without duress,

C. that the patient's intentions have been clearly interpreted,

D. that, as ascertained by clinical evaluation, the patient is not suffering from psychological depression or the effects of chemical use,

E. that the patient was, before refusing a treatment, fully informed of the range of available treatments and their consequences, as well as the consequences of nontreatment,

F. that the patient was encouraged to, and given agreed-upon time to, reconsider the decision,

G. that possible extenuating environmental factors (such as poor psychol/social environment) have been considered as potentially influencing the patient's decision,

H. that the patient was given the opportunity to summon relatives, friends, advocates, or professionals for alternative counseling in the matter.

Commentary
Law, Medicine & Health Care, Vol. 12, No. 3
Reprinted in the Minnesota Journal of Gerontology, Winter 1985

A Response to the Task Force on Supportive Care

by Jane D. Hoyt, Ed.M., and James M. Davies, M.A., L.P.N., J.D.

It is generally acknowledged that there has been misunderstanding about "supportive care" plans, and that guidelines would help clarify and direct the decisionmaking process. However, the guidelines and recommendations contained within the *Supportive Care Plan*, proposed by the Task Force on Supportive Care, are confusing and discriminate against persons with disabilities. Implementation of the recommendations could lead to inadequate care and neglect of a very vulnerable segment of our population, nursing home residents who are severely mentally or physically disabled. Because of concern about these possible outcomes, the Nursing Home Action Group of Minnesota has drafted alternative guidelines.[1]

There are five basic deficiencies in the *Supportive Care Plan*: (1) it would allow violations of the civil rights of persons with mental and physical disabilities; (2) it lacks definitions for some important terms; (3) it lacks sufficient protections for incompetent or questionably competent persons; (4) its tone and content encourage patients or their guardians to choose death-allowing care; and (5) it lacks adequate provisions for review of the decisionmaking process.

Discrimination Against People With Disabilities

The most disturbing aspect of the *Supportive Care Plan* is that Section II, entitled "For Whom Supportive Care Might Be Considered," wrongly includes patients with severe and irreversible mental disabilities and patients with severe and irreversible physical disabilities "where there may exist normal mental functioning . . ." By categorizing individuals with severe disabilities as potential candidates for supportive care only, the *Supportive Care Plan* becomes discriminatory against persons with disabilities. Aggressive research and rehabilitation efforts have improved the functioning of persons with every disease and disability cited in the *Supportive Care Plan*.[2] Listed as "potential candidates for supportive care plans" are victims of spinal cord injury, stroke, amyotrophic lateral sclerosis, emphysema, head trauma, and pre-senile and senile dementia. To label individuals with these infirmities as "potential candidates for supportive-care plans" discourages both professionals and consumers from hope and positive action.

Some patients who may seem beyond hope do have potential for rehabilitation. A registered nurse who had experience with rehabilitation testified in court to this effect:

> I saw a lot of nurses who had run into people maybe two to five years after they had had a stroke . . . or some other type of brain damage or dysfunction, and either a nurse or an aide or somebody would start to reach them in some way . . . it seemed as if a lot of these people took two to five years to get over the emotional adjustment to the trauma they had endured.[3]

Under the *Supportive Care Plan*, some individuals might be prematurely denied life-maintaining care and treatment before they have a chance to come to terms with their disability.

It is possible to develop guidelines that address the issue of treatment for dying adults while avoiding such discrimination. The guidelines drafted by the Nursing Home Action Group (NHAG) are based on the premise that the primary goal of health care givers is to encourage and promote the best physical, mental, emotional, social, and spiritual health of which each person is capable. The NHAG maintains that the criteria for making decisions about technology and ordinary and "extraordinary" treatment should be the same for all persons, regardless of physical or mental disability. A "death-allowing care goal"—care in which treatment is offered for comfort only but not for the purpose of maintaining life—is permissible only if the individual's bodily condition becomes, irreversibly and irreparably, terminally ill, and if death is imminent.[4]

Another shortcoming in Section II of the *Supportive Care Plan* concerns an inconsistency. The long Preamble states that these guidelines "do not address situations involving individuals who were never competent (newborns, mentally retarded)." However, since some incompetent newborns and many mentally retarded persons become nursing home residents, these individuals would very probably fall into the second or third category of patients for whom supportive care might be considered.

The Need to Define Terms

The *Supportive Care Plan* uses misleading and ill-defined terms. The term "supportive care" is itself very confusing, especially when people are facing a crisis; the *Supportive Care Plan* lacks a clear statement that "supportive care" may hasten death. To a frail person, the words "supportive care" may seem to mean the op-

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Ms. Hoyt is Chairperson and Mr. Davies is Vice-Chairperson of the Nursing Home Action Group/Minnesota, in St. Paul, Minnesota. On behalf of that organization, they recently drafted guidelines antithetical to those of the Task Force on Supportive Care.

posite of what is intended. A term like "death-allowing care goal," used in the NHAG Guidelines, is offered as a more accurate, properly descriptive term since such a care plan would allow death without preventive treatment, and could hasten death.

Another shortcoming in this document is the lack of a section devoted to defining language used throughout. Such terms as "hopeless," "principled approach," "meaningful interaction," and "high degree of certainty" leave the reader with little certainty of what is meant.

Consumers must have access to the information necessary to make thoughtful, protective decisions. The information must enable them to understand clearly their physicians' and facilities' values and policies.

Protection of the Questionably Competent Person

The *Supportive Care Plan* lacks sufficient protections for nursing home residents, especially those who are incompetent or questionably competent. It is well known that care and treatment in nursing homes often fall short of even minimal standards.[5] A 1982 study commissioned by the Health Care Financing Administration revealed that about 60 percent of the nation's doctors—the professionals who would have the most authority under the *Supportive Care Plan* for imposing "supportive care" plans—avoid nursing home residents.[6] Despite the clear evidence of problems in the care provided by nursing homes, there has not been a substantial improvement in the standard of care achieved in nursing homes.[7] Partial deregulation of the nursing home industry in the past few years has further threatened the health and well-being of nursing home residents.[8] The inception of the DRG system (Diagnosis Related Groups) has caused advocates to worry that nursing home residents might be returned prematurely from hospitals to long-term care facilities.[9] If the environment needlessly causes or facilitates the patient's decline, then it is unconscionable to harm the victim further by imposing a supportive-care plan. Society must focus on improving standards of care and treatment rather than on writing decisionmaking procedures which discriminate against persons dependent on poor-quality nursing homes or uninterested professionals.

The Supportive Care Plan is confusing and discriminates against persons with disabilities.

Many nursing homes have difficulty in properly following laws and regulations which are simpler than the guidelines found in the *Supportive Care Plan*. Evidence of this problem is nationwide and includes state health department reports showing that many nursing homes do not properly implement laws and regulations.[10]

The NHAG Guidelines provide that a fair evaluation of the health condition of any nursing home resident should include, but not be limited to, the following questions as they affect the individual resident:

> 1) Do the facility's nursing care, medical care, and social services meet state and federal standards?
> 2) Does the environment encourage meaningful, supportive interaction between residents and others?
> 3) Are meaningful, life-enriching activities available for all residents at the facility, and are residents encouraged to participate?
> 4) Are all residents' civil and human rights fully protected? Are residents encouraged to exercise these rights?
> 5) Is the resident free of medications which may cause: diminished activity and/or diminished motivation and/or other debilitating side-effects (such as lack of communication)?[11]

Such extensive considerations are lacking in the *Supportive Care Plan*.

The *Supportive Care Plan* needs to provide greater protection for residents who refuse treatment; the recommendations ignore many considerations that may arise in such situations. For example, the NHAG Guidelines propose that there should be detailed documentation in the medical record:

> 1) that the resident is legally AND clearly competent,
> 2) that the resident made the decision freely and without duress,
> 3) that the resident's intentions have been clearly interpreted,
> 4) that as ascertained by clinical evaluation, the resident is not suffering from psychological depression or the effects of chemical use,
> 5) that the resident was, before refusing a treatment, fully informed of the range of available treatments and their consequences, as well as the consequences of nontreatment,
> 6) that the resident was encouraged to, and given agreed-upon time to, reconsider the decision,
> 7) that possible extenuating environmental factors (such as those enumerated in the paragraphs above) have been considered as potentially influencing the resident's decision, and
> 8) that the resident was given the opportunity to summon relatives, friends, advocates, or professionals for alternative counseling in the matter.[12]

The Task Force gives essentially no acknowledgement to the regrettable fact that the immediate family does not always strive for the best interests of its members. Family members do not necessarily share the same values with respect to life-and-death decisions. To rely on the family, with no cautions regarding potential conflicts of interest, is untenable. Testimony before the United States House Select Committee on Aging in April 1980 and in March 1981 produced evidence of extensive abuse against the elderly within families.[13] In numerous states, the emergence of statutes for the protection of vulnerable adults, often based on child protection laws, reflects general recognition of and concern about abuse and neglect of adults with mental and physical disabilities.[14]

In contrast, the NHAG Guidelines stress that the best interests of the nursing home resident are paramount. The wishes of family and friends should be considered, but only insofar as they clearly reflect a sincere commitment to and understanding of the best interests of the resident. The wishes of family and friends to preserve life should be respected unless there is no beneficial medical way to do this. Decisions about nursing home residents who are severely disabled, who are poor, who leave inheritances, or who lack close relatives or friends should be monitored with particular care.[15]

> **The guidelines lack sufficient protection for nursing home residents who are incompetent or questionably competent.**

When a major medical or life-and-death decision involves an incompetent or questionably competent person, the NHAG Guidelines suggest either that a sincerely interested family member or friend assume the responsibility of guardianship, or that a guardian ad litem be appointed. The NHAG Guidelines create an exception to the requirement of guardianship when the nursing home resident is irreversibly, irreparably, and terminally ill, death is imminent, and a "death-allowing care goal" is being considered.[16]

The terminally ill resident should, like all other nursing home residents, receive emergency treatment for an acute, reversible emergency or injury (such as accidental choking or bleeding) not related to terminal illness. This issue is not adequately addressed in the *Supportive Care Plan*.

Encouraging Hope for People with Disabilities

Another deficiency in the Task Force's document is that it makes no recommendation that health care providers promote the value of life to patients with disabilities. Health care givers must be cautioned against promoting false despair. While allowing for decisionmaking before the onset of disability, guidelines should also provide for the possibility that people may change their minds once disabled. The individual's new, positive opinion of self-worth, and of the value of life after disability, should take precedence over any earlier decision to decline or discontinue treatment if disability occurs.

The Need for Unbiased Review

The *Supportive Care Plan* lacks adequate provisions for overseeing the decisionmaking process. While it does suggest that there be a bioethics committee in each nursing home, no provision is suggested for ascertaining whether the decisionmaking process is properly reviewed by a group outside the facility. Furthermore, no suggestion is made about the exact composition, authority, duties, or accountability of these bioethics committees.

The Task Force suggests that such a committee could be, at least initially, the facility's already established utilization review committee. Clearly, however, consideration of potential supportive care plans by the utilization review committee could conflict with other considerations, such as cost containment, which are already that committee's responsibility. In order to ensure the utmost protection of nursing home residents, bioethics committees would have to be independent of utilization review committees, and they would have to be supervised by some external agency.

Given the very different standards of care at different nursing homes, the criteria for regulating such decisions should be made outside the nursing home. This would lessen the possibility that a committee might be responsible for validating its own decisions to impose supportive care plans. Adequate review could be ensured through several ways. The NHAG Guidelines propose a nursing home human rights committee to advocate the civil rights and quality of services due all residents.[17] The human rights committee would function independently of the facility, and would be staffed by family and friends of residents, rehabilitation personnel from outside the facility, community members, and religious leaders.

Numerous groups advocating the rights of elderly and disabled persons oppose the type of discrimination found in Section II of the *Supportive Care Plan*. On April 12, 1984, at the request of the Nursing Home Action Group, the Board of the United Handicapped Federation, representing 25 organizations in the Minneapolis-St. Paul metropolitan area, adopted an affirmative resolution supporting the following principles:

> 1) The life of a person with mental or physical disabilities has the same intrinsic value as that of a person described as normal or healthy or ablebodied.
> 2) The primary goal of health care givers should be to encourage and promote the best physical, mental, emotional, social, and spiritual health of which each person is capable.
> 3) Orders for the withdrawal of treatment or noninitiation of treatment should never be given because of physical or mental disability.
> 4) Denial of essential, life-maintaining care and life-enhancing care because of mental or physical disabilities is a violation of basic civil and human rights.[18]

Certainly, no set of guidelines can resolve all questions raised by rapidly changing medical technology and by conflicting ethical values and medical opinions. It is hoped, however, that the *Supportive Care Plan: Its Meaning and Application* will be thoroughly revised to become clearer and more protective so that it does not jeopardize the lives of nursing home residents who have severe mental or physical disabilities.

References

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2. *See, e.g.*, Task Force of the National Institute on Aging, *Senility Reconsidered: Treatment Possibilities for Mental Impairments in the Elderly*, JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION 244(3): 259–63 (July 18, 1980).

Continued on page 134

Response to the Supportive Care Plan—References—*continued from page 105*

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4. NHAG Guidelines, *supra* note 1, at 10–11. The definition of the individual's bodily condition as "irreversibly, irreparably, and terminally ill, and death is imminent" is taken from Rabkin, M. T., *et al.*, *Orders Not to Resuscitate*, NEW ENGLAND JOURNAL OF MEDICINE 295 364–66 (August 12, 1976).

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11. NHAG Guidelines, *supra* note 1, at 11.

12. *Id.* at 8.

13. *Domestic Abuse Against the Elderly, Hearing Before the Subcommittee on Human Services of the House Select Committee on Aging*, 96th Cong., 1st Sess. (April 28, 1980); *Abuse of Older Persons, Hearing Before the Subcommittee on Human Services of the House Seldct Committee on Aging*, 97th Cong., 1st Sess. (March 23, 1981).

14. *See, e.g.*, CONN. GEN. STAT. ANN. §§469-14 to 25 (West Supp. 1980); MD. ANN. CODE art. 88A§§106-110 (1979); MINN. STAT. §626.557 (1980).

15. NHAG Guidelines, *supra* note 1, at 9.

16. *Id.*

17. *Id.* at 14.

18. Resolution adopted by the Board of Directors of the United States Handicapped Federation, St. Paul, Minnesota (April 12, 1984).

ERROR IN FOOTNOTE # 3

These are two separate civil rights cases.

State v. Hoyt was about First Amendment rights. A conviction for trespass was reversed by the Minnesota Supreme Court.

Hoyt v. St. Mary's Rehabilitation Center was about a restraining order to ensure that available emergency medical treatment would be given a patient should she ever need it. Hoyt v. St. Mary's was not reversed. The restraining order remains in effect.

More information on these two cases may be obtained from Jane Hoyt, 130 Southeast Warwick Street, Minneapolis, MN 55414

June 1984

Correspondence

Ordinary, Inhumane, and Supportive Care

Dear Editors:

The guidelines of the Task Force on Supportive Care, published in the June issue, are an important first draft of a policy on limited treatment plans for long-term care residents. But, the Task Force's approach represents a return to the flawed concept of "ordinary care" where medical care is partitioned into categories (life-extending vs. palliative therapies) in a way that circumvents a fully individualized evaluation of a resident's care.

Supportive care is defined in the document as "treatment to preserve comfort but not to prolong life." The assessment of when prolongation of life absolutely ceases to be a care plan objective is a fundamental ethical concern but a relatively less common clinical one. In a resident's balancing of the invasive, costly or dislocating burdens of medical treatment against the treatment's ability to maintain a marginally acceptable status quo, individual life-extending treatments weigh in quite differently. For most residents, the answer to the question, "Is life-extension a priority?" will be quite different if the subject is resuscitation vs. a short hospitalization to treat a kidney infection vs. a clinic visit for x-rays vs. the trivial inconvenience of urine cultures and a week of oral antibiotics vs. the benign daily medication for silent, potentially lethal conditions.

Nursing homes cannot be expected to develop two separate limited-treatment policies—one for the few, for whom life-extension is not a priority in any sense, and the other for the majority who would decline highly burdensome therapies while continuing to desire less burdensome, life-extending preventive and acute care. The Task Force's laudable emphasis on consent and individualized medical orders does not allay the danger posed to the majority of residents by policies defining life-extension as inappropriate when burdensome therapies are declined. It is easy to imagine a resident, content with a partially disabled existence, agreeing to a supportive care plan to limit resuscitation, intensive care, and even hospitalization. Later, a caregiver, seeing the supportive care plan, infers that life-extension is not a priority for this resident, and treats a potentially lethal bladder infection with analgesics instead of oral antibiotics or ceases treatment of an asymptomatic cardiac arrythmia precipitating sudden death because a "life threatening condition which . . . does not cause pain . . . normally would not be treated."

Policies guiding decisions to limit medical care in long-term care facilities should provide for a decision-making process where residents not only consent to their medical care, but define how they would choose in the trade-offs between burdens, benefits and competing priorities, as well.

Steven Miles, M.D.
Assistant Professor of Internal Medicine
Geriatric Research, Education, and Clinical Center
Veterans Administration Med. Ctr.
Minneapolis, Minnesota

Dear Editors:

Under the guise of compassion and humane consideration, the Task Force on Supportive Care has put forth an insidious and dangerous plan to rid society of those who it feels can no longer interact physically in a meaningful way with their environment, of those who offend society's sensibilities by approaching imminent death, and of those who fail to demonstrate an awareness of self. While the Task Force limits itself to this group today, it may, in the future, include handicapped infants and the mentally retarded.

The Task Force stresses that the final decision rests with the competent candidate or the family or friends of the incompetent beneficiary. Yet, by presenting its institutionalized program to people who have not realized that they have such a serious problem, the Task Force is subtly applying pressure on such people to accept that decision which will be most pleasing to society. Simply stated, it is telling the handicapped to avoid unpleasantness and quietly remove themselves. Society in the last five years has moved to reinforce the self-worth of the handicapped by mainstreaming them, but the Task Force wishes to prey on their self-doubts by whispering, "If you wish to do the noble thing and die, we'll help you to go painlessly."

By capitalizing on the much-publicized discussions of "death with dignity," the Task Force demonstrates the danger inherent in allowing human beings to determine at what point dignity requires death. What started as a movement to refrain from using heroic measures on a dying individual by writing DNR orders, has turned into a movement advocating not treating such curable diseases as pneumonia in patients with debilitating injury. Who will be next on the list of "undesirables?"

In conclusion, although the Task Force righteously stresses the essential dignity of human life by emphasizing maintaining dignity to the end, it is presumptuous in taking upon itself both the duty of defining the usefulness and worth of life and the responsibility of recommending the cut-off point at which life is no longer meaningful and worth preserving.

Aviva M. Halpert, R.R.A.
Risk Management Coordinator
Camelot Community Residence Program
Stony Brook, New York

Two Task Force Members Reply

Although time constraints were such that the Task Force was unable to draft a reply to the above comments, we would like to respond personally, based upon our involvement in the Task Force's activities.

Dr. Miles correctly points out that supportive care plans represent a continuum in terms of specific treatment options, rather than the extremes of maximal treatment and no treatment at all. The Task Force, aware of this continuum, focused on the individual's right to choose. Thus, it strongly emphasized throughout the document the importance of individualizing the supportive care plan and of involving

Continued on page 279

Correspondence—*continued from page 274*

the resident and his or her family to the greatest degree possible.

In response to Ms. Halpert's letter, we simply disagree with her opinion of the Task Force's motives and intentions. In fact, one of the central reasons we had in helping to draft the guidelines was the need to counter such views as those expressed in her letter. Reactions like hers, both here in Minnesota and elsewhere, have convinced us even more of the rightness of our decision to take on the necessary but onerous task of formulating general guidelines in admittedly controversial and value-laden areas.

Ronald E. Cranford, M.D.
Associate Physician in Neurology
Hennepin County Medical Center
Minneapolis, Minnesota

Barbara J. Blumer, J.D.
Broeker, Hartfeldt, Hedges & Grant
Bloomington, Minnesota

Correction in Commentary on the Supportive Care Plan

Dear Editors:
James Davies and I very much appreciated the opportunity to write the *Commentary* responding to the *Supportive Care Plan* in the June issue. We would like to note, however, an error in footnote 3 made by the editorial staff. The court case, *Minnesota v. Hoyt*, 304 N.W.2d 884 (Minn. 1981), is cited as though it were an appeal of *Hoyt v. St. Mary's Rehabilitation Center*, No. 773555 (Dist. Ct., Hennepin County, Minn. February 13, 1981).

In *Hoyt v. St. Mary's Rehabilitation Center*, I obtained a permanent restraining order to remove a do-not-resuscitate order from the medical chart of a resident in the facility. In *Minnesota v. Hoyt*, the Supreme Court of Minnesota reversed a conviction for trespass at St. Mary's Rehabilitation Center. I had been arrested after refusing to be barred from the facility after filing various health care complaints with official agencies. This access case does not pertain to the issue of withholding or withdrawing medical treatment and was not cited in the original paper.

Jane D. Hoyt, Ed.[illegible]
Nursing Home Ac[illegible]roup
St. Paul, Minnesota

Solidarity Day
Coalition

Celebrate the past, Issues for the present, Independence for the future

SOLIDARITY DAY, held on September 24th, 1983, was the coming together of some 33 organizations representing different disabilities, the purpose of which was to celebrate the 10 years since the 1973 Rehab Act, as well as to combine our forces to form a new action coalition.

Among the 33 groups which participated, representatives from over 20 groups attended the convention. These were:

Advocating Change Together
American Council for the Blind
Center for Education of Non-traditional Students
Currie Area Center
Division of Vocational Rehabilitation
League of Disabled Voters
Metro Center for Independent Living
Metro Deaf Seniors
Metro Handicapped Coalition
Mpls Mayor's Advisory Commission
MPLS Assoc for Retarded Citizens
M.S. Society
Nursing Home Action Group
Nursing Home Residents Advisory Council
Richfield Adult Disabled Group and Friends
School Legislative Issues Committee of the MN Speech & Language
Hearing Assoc
SPEAKOUT
Spina Bifida Assoc of MN
UNICORN
UHF

Several resolutions were passed, covering a range of concerns reflecting the disabled community. Among these was the following:

BE IT RESOLVED that the Solidarity Day Coalition opposes the initiation of "supportive-care-only" plans/orders, (the withholding of ordinary death-preventing medical treatment)on the basis of physical or mental disability.

This resolution passed unanimously.

arc Minnesota
Association for Retarded Citizens
3225 Lyndale Avenue South, Minneapolis, Minnesota 55408
(612) 827-5641 Toll Free 1-(800) 582-5256

July 13, 1984

To Whom It May Concern:

We wish to make you aware of the position of our organization with respect to the Supportive Care guidelines.

Our organization initially had serious concerns about the guidelines, particularly: (1) that the Supportive Care guidelines would obviously be applied to mentally retarded Minnesotans since mentally retarded people, like other Minnesotans, may live in nursing homes; and (2) that the "protections" afforded by the guidelines are not sufficient to adequately safeguard the rights and lives of mentally retarded and similarly disabled Minnesotans, and (3) that paragraph 2 on page 6 in particular, and other sections more generally, show a dangerous devaluing of the lives of persons who are mentally retarded, or have similar conditions, a devaluing which when combined with the lack of adequate protections in the guidelines could leave disabled people in a very vulnerable position.

Having taken our concerns to Supportive Care guideline task force members in previous months, we are now aware that changes needed to protect disabled Minnesotans cannot be made expeditiously.

We therefore wish to let it be known that our organization stands in strong opposition to any implementation of the Supportive Care guidelines. Further, that our organization will take action to assure that these guidelines are not implemented on the basis of any individual's mental retardation.

Sincerely,

Darlene M. Olson
Darlene M. Olson, Chair
Governmental Affairs Committee

DMO/cm

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CITY OF SAINT PAUL
OFFICE OF THE MAYOR

GEORGE LATIMER
MAYOR

347 CITY HALL
SAINT PAUL, MINNESOTA 55102
(612) 298-4323

July 25, 1985

TO WHOM IT MAY CONCERN:

Please be advised that the Saint Paul Mayor's Advisory Committee for Handicapped Persons met on July 24, 1985, 7:00 p.m., Room 356 City Hall and the following resolution was passed by the committee.

RESOLVED, that the Saint Paul Mayor's Advisory Committee for Handicapped Persons has deep concerns regarding the issue of the withholding of food and hydration, and

FURTHER RESOLVED, we believe that full access to food and water is a basic civil and human right and should never be withheld on the basis of physical or mental disability.

Wayne Wittman
Wayne Wittman, Chairman

Jeanette McDougal
Jeanette McDougal, Vice Chair

WW/JM/olp

arc minnesota
Association for Retarded Citizens Toll Free 1-(800)-582-5256
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Emil W. Angelica

BE IT RESOLVED THAT:

The Association for Retarded Citizens Minnesota has deep concerns regarding the issue of withholding food and hydration. We believe that full access to food and water is a basic civil and human right and should never be withheld on the basis of mental or physical disability, regardless of the presence of terminal illness.

Approved by the ARC Minnesota
Governmental Affairs Committee
July 25, 1985

Commentary

Minneapolis Star and Tribune, Friday, Aug. 9, 1985 P. 15A

Karen Ann Quinlan's fate might have been different

By Jane D. Hoyt

On June 11, the country terminated its death watch over Karen Ann Quinlan. Finally the woman hailed by right-to-die proponents as a "heroine" completed her appointed mission.

In a sense, we all benefited from this unfortunate woman's fate. Quinlan involuntarily brought to our attention numerous issues of medical ethics, most importantly that of substituted judgment, or deciding on someone else's behalf what medical treatment they might or might not have wanted. Many commentators, including the Star and Tribune (June 17), all but exulted over the presumed "dignity" of her death.

But some spectators had qualms. Quinlan may have been denied treatment and an environment to which she had a right. She may have deserved more than most people wish to acknowledge. Her legal case perhaps resulted in knee-jerk reactions to certain issues of medical ethics.

Quinlan's medical condition raises concern about apparent denials of preventive measures and of simple, ordinary treatment for curable conditions — conditions that may indicate a lack of the basic care due any nursing-home resident.

Her small body long ago curled into what was described as a grotesque "fetal ball" due to severe contractures. Possibly the nursing assistants did not give her simple, adequate range-of-motion exercises several times a day. According to "French's Index of Differential Diagnosis": "In all cases, [contractures] can be either prevented or minimized if appropriate physiotherapy is applied in the early stages; severe contracture may therefore be regarded as evidence of neglect in most cases." Lack of use of the body and mind lead to atrophy and dysfunction.

Quinlan's weight declined to as little as 60 pounds, half her normal weight, despite the nutrition she received through a nose tube. This type of nutrition sustains normal weight indefinitely if the patient is given adequate amounts of nourishment, if there is proper exercise and if the body is not challenged and drained by potentially lethal infections.

It was reported that, in her final days, Quinlan exhibited "more distress than in any of her last 10 years." This news followed reports months earlier that recurring lung infections were no longer being treated with the ordinary antibiotics that previously controlled this suffering.

Instead of dying with the "discomfort and intrusion of medical machinery" — the Star and Tribune's words — Quinlan evidently died with the discomfort of severe contractures, weight loss and the intrusion of carbon dioxide — pulmonary insufficiency due to lung infection.

From media reports we learned that she was kept for years in a locked, dimly lit, 8-by-10-foot nursing-home room with the shades drawn — hardly an environment to stimulate improvement. Even a healthy person would probably deteriorate in such surroundings. Her parents visited her often, and they certainly tried to look after her best interests. Yet we never heard reports of her being taken out of the institution for a change of scenery, or being given periodic reevaluations of rehabilitative potential. One can only hope that Quinlan was given such opportunities.

People who are comatose (but not "brain dead") may actually enjoy aesthetic, emotional, sensual or intellectual pleasures at some level that others cannot comprehend. These very vulnerable patients may also feel pain, loneliness, fear and despair. Research has shown that the vital signs such as the heart rate — even in comatose patients — have improved with nurturing, stimulating human contact.

Hope for people labeled comatose or "vegetative" comes from documented examples of so-called "hopeless" brain-damaged patients who regained significant abilities. Such cases usually involve aggressive treatment, rehabilitative goals and contact with people who are steadfast in their commitment to providing the patient with opportunities for improvement.

Considering how long Quinlan survived, she must have been very strong in some respects. One wonders whether her fate might have been different if she had received ordinary treatment (antibiotics) and much, varied stimulation from staff and volunteers.

Because some "hopeless" patients improve, and because medical science is advancing so rapidly, decisions to stop or withhold treatment from people who are unable to make choices must be based on the condition of the patient — and that condition must be imminently terminal. Otherwise, the risk of error, of casual extermination of the vulnerable among us, becomes too great.

Hopeless attitudes may determine a prognosis. Negativistic medical professionals may make a diagnosis and a prognosis and then feel threatened by any indication that their assessments were premature or wrong.

There are some truly hopeless cases in which the condition is irreversible and irreparable, and death is imminent. However, as aptly articulated by Dr. Ronald Cranford, neurologist and ethicist at Hennepin County Medical Center: "... maybe the reason (some coma patients) never recover is that they're never given the opportunity to recover. (Health-care givers) decide not to treat their complications and they die."

Quinlan's mother once reported that Karen, as a child, once commented that she "would never want to be kept alive by extraordinary means." We must be cautious about such "living wills," especially when the declarations are made by children. Medical technology is changing at such a rapid rate that decisions which may have seemed reasonable one or two years ago may next year seem irrationally pessimistic.

It would be better for competent adults to designate certain family members and close friends to make medical decisions for them if they

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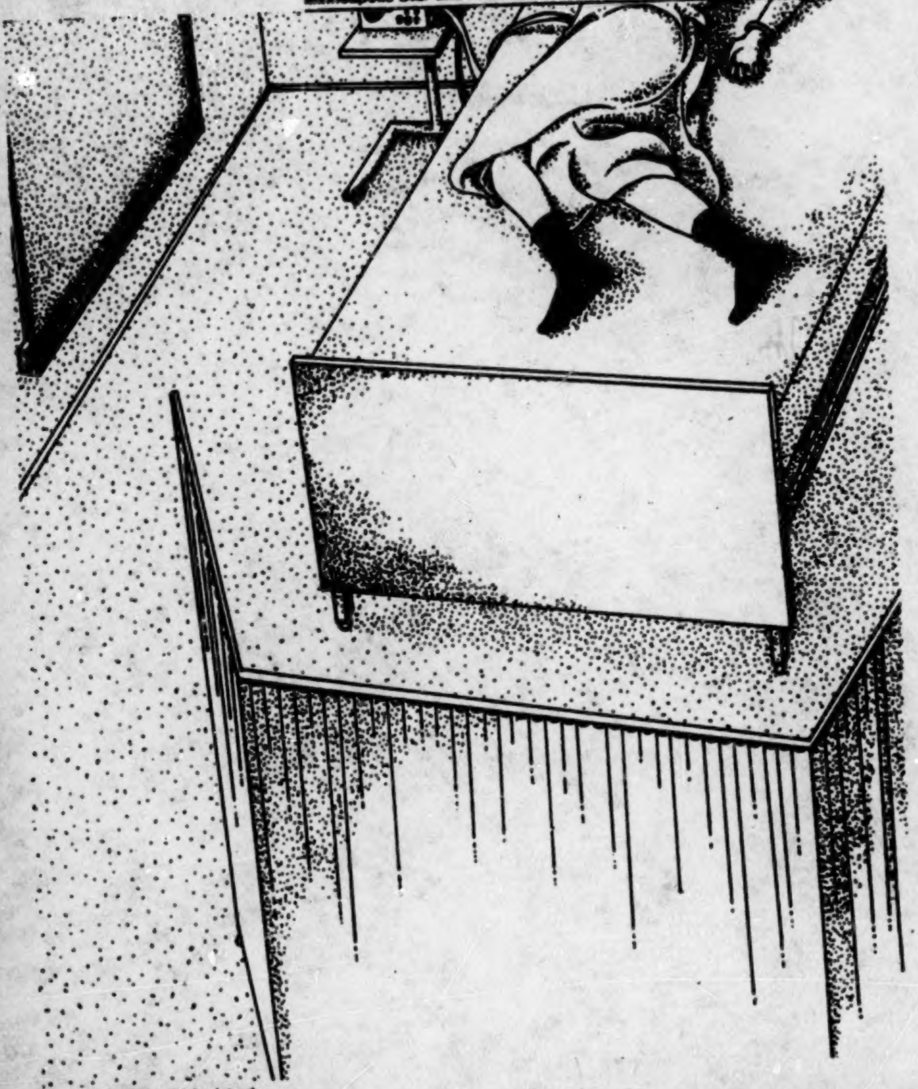

Illustration by Craig Macintosh

are unable. The designated decision-makers must know and share the patient's values, and they must be willing to participate aggressively in the decision-making process should the need arise. Appointing our own personal ethics committees, so to speak, and placing protective limitations on the circumstances in which such decisions are allowable, would make care givers more confident of decisions not to treat and would make patients more confident of receiving beneficial treatment.

Those who say they would "not want to wind up like Quinlan" often speak with both confidence and pathetic ignorance. No one in his or her right mind would "want" to have severe brain damage. But until one is severely disabled, one can hardly know and judge such a life.

Perhaps we need to consider which would be worse: to halt treatment mistakenly for someone who is no longer able to communicate a changed, more positive attitude toward the worth of life after disability, or to treat someone mistakenly who, after becoming disabled, wants to die.

It appears that the vast majority of people, once disabled, want to hold onto life. News articles stated that Quinlan "constantly fights for life."

It is our societal responsibility to help people with disabilities reach their highest potential, and to help their families and close friends be a source of strength for them.

The choice should not be between dying, as Quinlan did last June, and living as she apparently did this past decade — deprived of normal human contact, varied stimulation, exercise, nourishment and, finally, ordinary medications.

Jane D. Hoyt is chairperson of the Nursing Home Action Group.